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## Family caregiving and dementia: stresses, satisfactions and mediating factors in taking on and continuing in the caring role

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Version: Version of Record

Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.21954/ou.ro.0000e28d>

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FAMILY CAREGIVING AND DEMENTIA:  
STRESSES, SATISFACTIONS AND MEDIATING FACTORS  
IN TAKING ON AND CONTINUING IN THE CARING ROLE

A thesis submitted in partial fulfilment of the requirements of the Open  
University for the degree of Doctor of Clinical Psychology

NOVEMBER 1999

SALOMONS  
CANTERBURY CHRIST CHURCH UNIVERSITY COLLEGE

AWARD DATE: 5 November 1999

### **Acknowledgements**

I would like to thank my managers and colleagues for their support over the last two years. I am especially grateful to Jane Volans for her advice and encouragement and to Liz Francis.

I would also like to thank all the people who took part in the project.

## **Abstract**

### **Background and aims**

The predominant focus of research into family caregiving and dementia has been on the stresses of caring. This project aimed to look at both the stresses and satisfactions derived from caring for a close family member with dementia, and to explore mediating factors in the decision to take on and continue in the caring role.

### **Design and participants**

A two part, non-experimental design was used. Qualitative methods were used to look at the subjective experiences of two groups of carers, 5 spouse/partners and 6 adult child carers. Quantitative data were obtained from a postal survey of 115 people from a clinical service.

### **Measures**

Data were collected from semi-structured interviews and from standardised questionnaires on mood state and on the stresses and rewards of caring.

### **Results**

The main stresses for carers were related primarily to emotional and relationship factors and to practical restrictions imposed by the caring role. The main satisfactions derived from caring were also related to emotional and relationship factors, including



the well-being of the care recipient. For many carers the role had evolved over time and some felt they had not made an informed decision in taking on care.

### **Implications**

An instrumental approach to the effects of caring may be less helpful than focusing on the carers' goals and the extent to which they perceive themselves as achieving these.

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# **1. INTRODUCTION**

## **1.1 Background and overview**

For many years the focus of research into caring for someone with dementia has been on identifying the range of associated negative mental health and physical health consequences and clarifying the specific stressors that determine these negative outcomes. It is only relatively recently that some researchers have recognised potential rewards or satisfactions that may be experienced by carers, and little work has been done to further investigate these factors.

The aim of the current project was to explore both the stresses and rewards of caring and to look at mediating factors in the process of taking on and continuing to care for a close family member with dementia.

The literature review will give a general background to the area by looking at dementia and caring, before moving on to an examination of the effects of caring, a theoretical model for understanding the process and experience of care-giving and mediating factors in the way people cope with care. Finally, the clinical background to the present study will be explained and the research questions arising from the literature and clinical experience will be given.

## **1.2 Dementia**

### **1.2.1 Definition**

There are many different definitions of dementia. One of the most widely used is taken from a report by the Royal College of Physicians (1981), subsequently adopted by the World Health Organisation (1986): “Dementia is the acquired global impairment of higher cortical functions including memory, the capacity to solve the problems of day to day living, the performance of learned perceptuo-motor skills, the correct use of social skills, all aspects of language and communication and the control of emotional reactions, in the absence of gross clouding of consciousness. The condition is often progressive though not necessarily irreversible.” More concisely Lishman (1987) defines dementia as “an acquired global impairment of intellect, memory and personality.”

### **1.2.2 Prevalence and types of dementia**

The prevalence of dementia increases sharply with age. Hofman, Rocca and Brayne (1991) summarised epidemiological surveys and concluded that 5% of all people over 60 years of age may be expected to suffer from dementia, rising to more than 30% of people over 90. Keen (1992) suggested in his review of dementia that there was a distinction between normal aging and dementia, but that many of its signs and symptoms were best conceived as being on a continuum.

Katzman & Kawas (1994) suggest 57% of people with dementia have Alzheimers Disease (AD). Additional forms of dementia include other degenerative dementias, vascular dementias, infective dementias, toxic dementias and those caused by

metabolic problems, space occupying lesions and neurological insults (McKeith, 1994). Most of the research in the area of dementia has been conducted with people who are diagnosed with AD, although at present a firm diagnosis can only be given at post-mortem.

### 1.2.3 The need for care and informal carers

The nature of the dementing process means that eventually most sufferers will need considerable help and support. With the progressive loss of cognitive, social and recreational skills, in the later stages of the condition people are generally unable to perform even basic acts of self care.

Keady & Nolan (1996) point out the effects of the dominance of the medical model of dementia, which resulted in hospital-based institutional services and long-stay care provision. The need to develop more community based services for dementia arose from the recognition that the 'old old' have increased as a percentage of the population due to demographic changes, and are set to continue increasing into the new millennium. Because the prevalence of dementia increases with age, this has had serious implications for the provision of services to people with dementia and their carers. It was realised that statutory services could not hope to meet the rising need for residential or nursing care, coinciding with a more general move towards community care since the 1970s, driven by government policies (e.g. The NHS and Community Care Act, 1990).

Thus underlying the extensive research into care giving has been the necessity to ensure that carers are able to continue their care giving role for as long as possible,



creating a tension between those services concerned with the well-being of the care giver, and those encouraging the continuation of care giving (Moriarty & Levin, 1993).

### **1.3 Caring**

#### **1.3.1 Definition**

Definitions of caring are quite varied and have been criticised for conceptual confusion by Nolan & Grant (1992), who also suggest they place undue emphasis on the instrumental aspects of caring to the exclusion of less obvious and less easily measureable aspects of caring, such as the provision of emotional care and support. Further problems associated with the use of different definitions are the limits this imposes on comparisons and on generalisation.

Definitions of care giving are generally based on self-identification or operational definitions – usually focusing on the assistance given with activities of daily living. Thus Green (1988) defined a carer as ‘A person looking after or providing some form of regular service for a sick, handicapped or elderly person living in their own or another household.’

#### **1.3.2 A model of caring**

Bowers (1987) used grounded theory to look at the experiences of a sample of adult children caring for a parent with dementia, and proposed a model to understand the process and experience of caring in these circumstances. Arguing that caring should

be defined by purpose rather than task, Bowers maintained that many components of caring are not instrumental, but 'invisible' even to the dependant.

She proposed five purposes of care: anticipatory care and preventive care, neither of which require direct 'hands on' intervention; supervisory care, when direct assistance may be required; instrumental care, when the carer undertakes practical and or physical care for their dependant; and protective care, the aim of which is to maintain the sense of independence and self esteem of the dependant. Bowers suggested protective care was the construct which carers found most stressful, but also the one to which they attached the greatest importance.

### 1.3.3 The demographics of caring

The most frequent form of care giving is for a spouse (UK Census, 1990). Gasper (1980) surveyed 230 referrals to a dementia service and found that 56% of men with dementia lived with a spouse, compared to 26% of women. Saad, Hartman, Ballard, Kurian, Graham and Wilcock (1995) looked at the demographic features of the carers of 125 consecutive referrals to a clinical service, 109 of whom had an informal carer in contact at least once a week. Of these, 52% were aged 65 or over, 62% were women and 38% men. 42% were spouses, 39% children, 4.6% siblings, and the rest were more distant relatives or friends.

## **1.4 The effects of caring**

### **1.4.1 Introduction**

The early emphasis on the effects of caring for someone with dementia was on the burden, stress and difficulties of the process. Measuring these was the focus of much interest, and Grad & Sainsbury (1965) were the first to make a distinction between the objective and subjective aspects of carer stress/burden. Measuring the effects of caring has proved problematic, depending as it does on a coherent theoretical underpinning, but advances have been made in this area.

### **1.4.2 Mental Health**

Care giving is associated with negative mental health consequences, particularly increased rates of depression. Estimates of the prevalence of depression among carers of people with dementia vary, depending partly on different sampling methods, different definitions of caring and different ways of assessing and defining depression. Collins' (1992) review highlighted that levels of distress and morbidity are lower in randomly selected community samples of carers than in samples obtained through clinical settings, and that gender differences are also smaller. Intuitively it makes sense that clinical samples are more likely to be more stressed. Most studies report prevalence figures of between 30-50%. For example, Saad et al (1995) reported a figure of 29.4% in their clinical sample, while Zanetti, Frisoni, Bianchetti, Tamaza, Cigoli and Trabucchi (1998) found a prevalence of 30% in their sample of carers from a cross-sectional study of 103 patient-carer dyads referred to a dementia unit in Italy.

### 1.4.3 Physical health

Kiecolt-Glaser, Dura, Speicher, Trask and Glaser (1991) found evidence of decrements in immune system functioning among care giver spouses of AD patients, as well as increased rates of depression relative to matched controls. A number of studies have found an interaction between actual or perceived poor health on the part of the care giver and increased vulnerability to depression. Zanetti et al (1998) found that the care giver's perceived health status was a strong independent predictor of depressive symptoms, but it was unclear whether poor physical health was a result of the care giving role, or whether carers with less physical 'reserve' to assist in heavy care giving tasks experienced increased burden.

### 1.4.4 Grief reactions

Theut, Jordan , Ross and Deutsch (1991) suggested that carers of people with dementia can experience an anticipatory grieving process, drawing on earlier ideas that unconscious mourning may anticipate the death of a significant person, making the actual loss less painful. Garner (1997) pointed out that the awareness of 'losing' the person with dementia may begin early in the dementing process, as subtle changes in personality and the self become apparent, and therefore that the pattern of psychological distress in caring for someone with dementia fits a concept of current grief for actual loss. In anticipatory grief the true reality of the loss cannot be realized until death has occurred and the person is no longer available for interaction, but Garner points out that this non-availability has already occurred as dementia progresses and the patient is unable to fully engage in the mutuality of the relationship.

#### 1.4 5 Measuring the effects of caring

This has focused almost exclusively on attempting to quantify carer stress or burden, but Nolan & Grant (1992) suggest the development of valid and reliable measures has been hampered by different definitions and conceptual understandings of burden, making comparison across studies difficult.

They point out that some of the earlier devised scales of carer burden (e.g. Zarit, Reever and Bach-Peterson, 1980; Robinson, 1983, cited Nolan and Grant, 1992) assume equivalence of stimuli and mask the relative contribution of different forms of burden to the overall burden score.

Cantor (1983) made a distinction between the degree of strain and the impact on a carer's life, seeing these as separate but related consequences of caring. Poulshock & Deimling (1984) devised an assessment based on a three part model, consisting of elder impairment (the amount of help required with activities of daily living, or ADLs, and the degree of cognitive impairment), burden (the subjective individual responses to impairment) and impact (objective changes in carers' lives). The model highlighted the mediating role of subjective perceptions, which were further developed by Pearlin, Mullan, Semple and Skaffs (1990) in the Stress Process Model, which we will look at in the next section.

Vitaliano, Russo, Yount, Teri and Maiuro (1991) concluded that measures to assess the impact of informal caring differ in content domain, have been developed in widely differing and often very small samples and have frequently failed to demonstrate validity. Furthermore, it is not clear whether there is a linear relationship between the

level of cognitive deterioration and carer burden, which is important to clarify since some studies have taken the extent of cognitive impairment as a measure of demand on carers. Zarit, Todd and Zarit (1986) found that burden was highest in the middle phases of dementia, and hypothesised that this might reflect the problems associated with managing behavioural disturbance, which may be most marked at this stage.

Until the early 1990s there was no systematic attempt to measure potential rewards derived by carers, despite some evidence that caring could provide satisfaction, especially when a good carer-dependant relationship was maintained (e.g. Motenko, 1989). Nolan & Grant (1992) devised two associated questionnaires, the Carers Assessment of Difficulties Index (CADI) and the Carers Assessment of Satisfaction Index (CASI) as part of their extensive evaluation of a respite care scheme in Wales. The CASI lists potential satisfactions of caring, which are given a rating. Nolan & Grant found that the main sources of satisfaction in their sample related to the giving of pleasures that provided happiness to the dependant, maintaining their dignity and keeping the dependant out of institutional care. It is worth noting that the dependants in their sample did not necessarily have a dementing condition.

## **1.5 The theoretical perspective on care-giving**

### **The Stress Process Model**

This is the most widely used model for conceptualising the effects of care giving in dementia, devised by Pearlin et al (1990) to guide their longitudinal study of family care-givers of someone with dementia. The model postulates that care giver adaptation depends on the point the care giver is at in their care giving 'career', and

includes the notions of stress proliferation, by which the effects of stressors can spill over and effect other areas of a carer's life, and stress containment, the process by which carers can limit the effects of stressors by drawing on their available social, economic and psychological resources. Stressors can be primary (i.e. directly related to the care recipient's disability and to providing assistance), or secondary (i.e. changes in the care giver's life resulting from their efforts to respond to primary care tasks). The distinction the model makes between objective and subjective dimensions of primary stressors reflects Lazarus & Folkmans' (1984) finding that the meaning someone places on an event is a better predictor of its impact than an objective measure of the stressor.

Pearlin et al suggest three main components of primary subjective stressors: role overload, when the carer becomes physically or emotionally depleted by their caring role; role captivity, when the carer feels trapped by their care-giving responsibilities; and loss of relationship with their dependant. They have found that increases in role overload and captivity are associated with higher levels of distress.

## **1.6 Coping with care**

In looking at how people cope with caring for a family member with dementia we will consider research on a number of mediating variables, including patient related factors, coping styles, social support, the effects of gender and type of relationship, and the interaction with a sense of self, values and cultural expectations.

### 1.6.1 Patient related variables

An early study by Greene, Smith, Gardiner and Timbury (1982) showed that personal distress in the carer was mainly related to the amount of apathetic and withdrawn behaviour of the patient, whereas negative feelings towards the patient were related to the degree of disturbance of the patient's mood. Donaldson, Tarrier and Burns (1997) reviewed seventeen empirical studies looking at the association between symptoms of dementia and adverse consequences of caring. They concluded that there was a relationship between non-cognitive features of dementia (e.g. psychotic symptoms, behavioural disturbance) and care giver burden. However, whether or not it is valid to regard behavioural disturbance as a 'non-cognitive feature' of dementia is debatable, since it could be argued that many instances of behavioural disturbance reflect the underlying cognitive impairment.

LoGuidice, Waltrowicz and McKenzie (1995) found that deficits of behaviour were more closely related to measures of carer burden than excesses of behaviour. In a study of subjective appraisals of primary stressors in AD carers, Ford, Goode, Barrett, Harrell and Haley (1997) found that while memory and self care deficits were relatively common, these were rated as less stressful than behavioural problems by male and female carers. The most stressful behaviours identified by carers were: dangerous behaviour, getting lost, embarrassing behaviour, waking people at night, agitation and suspicious or accusative behaviour. The only memory problem rated as significantly stressful was asking repetitive questions.

Haley, Levine, Brown and Bartolucci (1987a) suggested that self care problems are more clearly related to cognitive decline, and may be seen as more predictable than



behavioural problems - as we will see in the next section, research on carers drawing on the reformulated learned helplessness model has indicated that a sense of control is an important variable for carers. A two year longitudinal study concluded that care givers' abilities to tolerate problem behaviours increased as the disease progressed, and that by follow up, some of the most troublesome behaviours, including wandering, paranoid accusations and restlessness were no longer manifest by many patients, while deficits in the activities of daily living were more prominent (Zarit, Todd and Zarit, 1986).

The most glaringly obvious 'gap' in this literature is any mention of the experience of being cared for, or the positive aspects of being in such a relationship for either party. Stueve (1982) observed that research focusing on older people as care recipients only may overlook their interpersonal contributions to their care givers. Keady, Nolan and Gilliard (1995) interviewed people with dementia attending a specialist treatment centre. Commenting on the wish to be seen as individuals in their own right, rather than appendages to a carer, one said "I have the right to consider myself a nuisance, but this does not mean that everyone else has to." The terms dependant and care recipient are used inter-changeably in this report, but it is acknowledged that neither is ideal. Because the thrust of policy making in the area of dementia is aimed at keeping people in the community, combined with a sense of therapeutic nihilism, the focus of services has been on carers rather than patients. Given that there are negative consequences for carers associated with caring, it is easy for the perspective of the care recipient to be overlooked.

### 1.6.2 Coping styles and strategies

Pearlin and Schooler (1978) defined coping as the response people make to stressors to avoid their harmful consequences. The three main identified coping styles are problem focused, cognitive and emotion focused (Lazarus & Folkman, 1984), although Kramer (1993) proposed that relationship focused strategies have been overlooked. Relationship focused coping involves interpersonal regulation processes aimed at establishing, maintaining, or disrupting social relationships.

In Kramer's study of 72 wife caregivers of husbands with AD, emotion focused coping was the only significant predictor of depression, while problem focused and positive emotion focused strategies predicted satisfaction. Problem focused and cognitive coping are related to lower distress and emotion focused coping to higher levels of distress (Vitaliano et al, 1991).

Saad et al (1995) found that active management strategies were significantly inversely associated with depression, but did not find significant differences in coping strategy between men and women. Billings & Moos (1981) demonstrated that women are more likely to use 'avoidance' coping, while men tend to describe themselves as more 'active' copers, who use more mastery in their coping responses, when mastery refers to a sense that people have control over their own lives.

A number of researchers have drawn on the reformulated helplessness model of Abramson et al (1978), which states that internal, global and stable causal attributions for important, uncontrollable, aversive outcomes predict both future expectancies of uncontrollability and symptomatic manifestations of helplessness. Pagel, Becker and

Coppel (1985) and Morris, Morris and Britton (1989) both looked at the role of perceived control and the processes of attribution. Pagel et al, in a longitudinal study of 68 spouse care givers, found that perceived loss of control combined with internal causal attributions for events related to their spouse's condition predicted higher levels of depression than did either factor alone. Similarly, Morris et al found depression and strain were significantly correlated with the care givers' perceived lack of control over their own emotional reactions and over their dependents' behaviour.

Seeking knowledge of the condition of dementia can also be seen as a coping strategy, and when they looked at knowledge, coping and morbidity in 109 carers, Graham, Ballard and Sham (1997) found that more knowledgeable carers experienced significantly lower levels of depression but higher rates of anxiety. They speculated that the elevated anxiety levels may relate to greater anticipation of loss as a result of knowing the likely course of decline. However, it is also possible that more anxious carers tend to seek out knowledge. Men were significantly more knowledgeable than women, which may reflect differences in active coping.

### 1.6.3 Social support

It might be supposed that increased levels of social support would have a positive impact on care giver stress, but the evidence is mixed. Zarit, Reever and Bach-Peterson (1980) found that carers' levels of perceived burden were decreased by family visits, but Levin, Sinclair and Gorbach (1989) found no association between distress and the number of visits from family and friends, or the carers' attitudes towards the amount of help given by other. Gilhooly's (1984) results showed that

help from community nurses and home help increased morale, but that this was not affected by social contact with friends. Satisfaction with informal help was significantly related to mental health and morale.

Levin et al (1989) also found that male carers were more likely to receive practical support from the home help service, and Murray (1995) questions whether lower levels of support may be contributing to lower morale in female carers.

#### 1.6.4 The effects of relationship type

The evidence on the effects of relationship type is addressed separately to that on gender, but it is recognised that gender may be a confounding variable.

##### Adult child carers:

Horowitz (1985) provided a detailed comparative study of the experience of a community sample of sons and daughters caring for a parent. There were significant differences in the type of care given – daughters were more likely to give ‘hands on’ assistance and to score higher on measures of care giving involvement and objective burden. Sons were less likely to think they had to sacrifice anything, neglect family responsibilities or interrupt leisure pursuits or future plans in order to care for their parent, and they expected ‘active’ support from their spouses. Interestingly, the daughters in the sample were more likely to expect their husbands to remain ‘neutral’ and not voice objections to their care giving activities. Further differences in objective burden were demonstrated by Charlesworth, Wilkin and Durie (1984), who found that daughter carers were more likely to be co-resident.

Walker, Martin and Jones' (1992) study of 141 mother-daughter dyads, in which the mother was physically, not cognitively impaired, concluded that the role of perceived intimacy was a major factor for daughters: those with better relationships experienced fewer care giving costs. They hypothesised that caring could confer gains on the care giver, either through the act of caring or through benefits derived from the relationship. While caring for a parent with cognitive impairment is obviously qualitatively different, the conclusion regarding the role of intimacy raises again the importance for women carers of the reciprocal nature of their relationship with the care recipient. Gilhooly (1984) reported that daughters with a very close pre-morbid relationship to a care recipient parent with dementia seemed likely to experience higher levels of strain. Collins (1992) suggests that women caregivers may have generally closer ties to their dependants, and may find the loss of mutuality in dementia particularly stressful.

#### Spouse carers:

There is some evidence that husbands and wives may have different ways of caring for and managing the process of care. Brody (1985) suggested women may take with them into the role a model of care based on child-parent interactions, while men may have a model derived from their working experiences, emphasising delegation of responsibility and recognition of limitations. Zarit, Todd and Zarit (1986), in their two year longitudinal study of spouse care givers, found that initially husbands reported less stress than wife care givers. They were observed to adopt an instrumental approach to daily problems, while wives had difficulty maintaining the emotional distance necessary to consider alternative strategies for managing

problems. At follow up the gender differences had disappeared, and many wives had adopted a more instrumental approach.

Collins and Jones (1997) used a matched comparison of husband and wife carers (N = 24 in each group). 65% of the wives and 38% of the husbands met clinical criteria for emotional illness, although neither the behaviour of the care recipient nor the objective workload predicted the wives' greater strain. Wives were involved in more 'hands on' care and household chores, while husbands were more involved in 'managerial' tasks, such as transport and finances. Wives were more likely to believe they were not coping and to feel they would be unable to continue for much longer. They also felt significantly more obliged to continue caring and to wish they could give it up. They reported less satisfaction with their marital relationships, and the authors concluded that the loss of reciprocal emotional support was a particular problem. Husbands were more likely to state that caring gave them a purpose in life.

Fitting, Rabins, Lucas and Eastman (1986) found male spouse carers were much more likely than females to report an improvement in their marital relationship since the onset of dementia. Barusch & Spaid (1989) found wives tended to report feeling more angry and having more arguments with their spouses, and felt more frequently that they could not cope. Men reported feeling greater effectiveness in coping with care management problems, finances and health related problems, while women reported coping more effectively with personal psychological problems. Arie (1989, cited Collins, 1992) said 'Some men may actually be sustained by a caring role which for them is more novel than it is for a wife, giving back or enhancing some of the purpose and direction lost at retirement.'

### 1.6.5 Effects of gender

There is considerable evidence that women tend to find caring for a family member with dementia more stressful than men, although this runs counter to widely held beliefs that women are more 'natural' care givers. In the Collins and Jones (1997) study already described, both male and female carers thought women were better suited to care and found it easier. Because many studies have obtained their results on the basis of measures of subjective burden/strain, it is important to bear in mind gender differences in emotional expressivity (Briscoe, 1982) and the fact that women tend to have higher levels of emotional disturbance generally.

Miller (1987) suggested that instead of being seen as an extension of the nurturing role, caring can be seen instead as an extension of the authority role, which is more closely associated with men than women. Miller reported that women carers found it hard to assume authority over their dependant husbands, especially if the husband had been seen as an authority figure in their pre-morbid marital relationship. Male carers in Miller's study appeared to be at ease in taking responsibility for the instrumental aspects of care, and it is suggested by Morris, Woods, Davies and Morris (1991) that men may transfer the scheduling and task-orientated approach from work.

Gutmann (1987) proposed a developmental change in sex role differences during middle and later life, in which women may become more instrumental and assertive, while men can become more nurturant and expressive. Collins (1992) points out that the strain can be compounded for middle aged women, who may be in the process of relinquishing child care responsibilities and finding alternative sources of gratification. Zarit et al (1986) suggested wife carers may view their later years as a

time for personal growth and new opportunities, and resent becoming carers of their husbands. Husband (1987) found male carers were more likely to maintain other interests and relationships and more readily 'forget' the situation when away from it, thus experiencing less pervasive subjective strain.

It would appear that the provision of care has different meanings and implication for male and female carers, perhaps drawing on differences that are not directly related to the caring situation, but to cultural and personal expectations about the nature of work and relationships and the process of construing something meaningful or gratifying from our experiences.

#### 1.6.6 Interactions with a sense of self and values

Lawton, Kleban, Moss, Rovine and Glicksman (1989) conducted a factor analytic study of care giving appraisals, suggesting that caring may be appraised in positive as well as negative ways, and that a full understanding of care giver outcomes requires consideration of both. Lewis & Meredith (1988) found that care givers who provide care out of reciprocity and appreciation have a more positive evaluation of the care giving situation. For care givers, 'outcome' may have meanings other than symptoms or burden, including the extent to which they feel they have achieved their objectives, or that the sacrifices made have been worthwhile. Aneshensel, Pearlin, Mullan, Zarit and Whitlach (1995) found that although such positive attributions appear to be very important for many care givers, they do not result in significant containment of stress over time. Orbell, Hopkins and Gillies (1993) note that people may derive self worth from their identification as carers and suggest satisfaction may be influenced by elder impairment in two ways. Carers of the cognitively impaired may feel inadequate to



meet the needs of the behaviourally disturbed by bringing about any change in behaviour, or they may cease to receive feedback from their dependant which would make them feel appreciated.

Orbell et al conclude that willingness to provide informal care is related not just to the strain experienced, but also to the rewards derived from the caring relationship. As has been pointed out previously, women may be less likely to obtain these rewards in the context of a progressive dementing condition than men, who may be less dependent on continuing emotional 'mutuality' for the maintenance of a 'good' marital relationship. Orbell et al suggest that relatively little work has been concerned with the decision to continue caring, rather than to seek institutional care for a relative with dementia, and point out the relevance of theories of work motivation, which stress the intrinsic psychological rewards associated with work, including role competence. (Herzberg, 1966; Hackman and Oldham, 1976).

Perceived competence and personal orientation have been shown to be related to care giver strain. Goodman, Zarit and Steiner (1997) looked at the effects of personal orientation on 245 primary care givers of relatives with dementia. They found that feeling competent as a care giver was associated with less stress. Graham et al's (1997) study showing that more knowledgeable carers experienced lower levels of depression, also showed that more knowledgeable carers were more likely to have reduced expectations of their dependants' abilities, to make positive comparisons, and to feel competent and confident as care givers.

An interesting study by Haley, Roth, Coleton, Ford, West, Collins and Isobe (1996) suggested a strong influence of cultural and personal expectations in accounting for the apparent differences in subjective burden reported by matched black and white care givers in their American sample. Using data obtained from 123 white and 74 black family care givers of a relative with dementia, they found black care givers appraised patient problems as less stressful and reported higher self efficacy in managing care problems and less depression than did white care givers. Haley et al suggest black care givers are more tolerant of disturbance in family members than whites: black families tend to bring relatives for assessment only after greater severity of impairment is present than in white families. They suggested that older women in these families may be given special regard, independent of their cognitive and behavioural functioning, making decline in these areas less important than to white families. And they proposed that caring for an older relative may be more culturally normative in black families, whereas white care givers are more likely to report that care giving disrupted a life plan or highly valued goal, such as retirement or travel.

### **1.7 The effects of the care giving 'career'**

The effects of the duration of care are unclear, and apparently conflicting results have been obtained from longitudinal studies. Gold, Reis, Markiewicz and Andres (1995) found that relatives still caring for someone with dementia at home after two years showed a decrease in mental health, while Zarit & Whitlach (1992) concluded that although the level of psychological distress in spouse carers tended to remain stable or increase, that of daughters generally decreased. Pot, Deeg and Van Dyck (1997)

reported on a two year longitudinal study in The Netherlands, comparing three groups of carers: those who continued to care at home, those whose dependant had been admitted to institutional care, and those whose dependant had died. Their results demonstrated a decrease in mental health (assessed by the General Health Questionnaire and the Symptom Checklist 90) among those still caring at home, no changes among those whose dependant was in institutional care, and an increase in those whose dependant had died.

Zarit, Todd and Zarit (1986) focused on the factors associated with nursing home placement in another two year follow up study of 64 spouse carers. They found that placement was more strongly associated with subjective factors – especially the subjective perception of burden – than with objective indicators of the severity of dementia. In apparent contrast to Pot et al, Zarit et al found that the ability to tolerate care giving problems increased with the care recipients' cognitive decline, and they pointed out that some of the more troublesome behaviours diminished or ceased during the period of the study.

### **1.8 Summary of the research findings most relevant to the present study**

As we have seen, the dominant focus of research on the effects of caring has been on the negative consequences, but there has been little work on the potential satisfactions carers may experience. Bowers 'purposes of care' model and the Stress Process model provide useful frameworks for conceptualising the experience of caring for someone with dementia, the latter highlighting the major role played by subjective appraisals in determining outcome. Among the mediating factors in the care process,

there is a growing body of evidence suggesting there are gender and relationship differences, in which men tend to adopt a more instrumental approach to care than women, which is associated with lower levels of stress. Different theories have been put forward to account for this, including changes in gender role and the differential use of work related 'management' models or child-rearing related 'nurturing' models by men and women.

Another area of sparse investigation has been in the decision to continue caring within the family rather than opting for institutional care, and it has been suggested that theories of work role motivation, stressing the intrinsic psychological rewards of work, may contribute to our understanding of the caring process, linking with some existing evidence that carers who feel more competent tend to feel less stressed.

## **1.9 The present study**

### **1.9.1 Clinical background to the present study**

The researcher was involved in a two year community dementia project that received funding from the Department of Health from 1996 to 1998, devising a detailed study of carer satisfaction that employed a postal survey and structured interviews. Part of this was submitted previously to the D. Clin. Psych. programme as a small scale research project. The present study was in part an extension of this exploration of carers' experiences, drawing on unreported data from the postal survey and further semi-structured interviews with a sub-sample of the clinical population, which were analysed using qualitative methods. Further details of the initial study are included in

the methodology. The present study focused on those aspects of the caring process that contribute to stresses, rewards and perceived competence in the role, as well as factors that influence taking on and continuing the care-giving role. Following Orbell et al's suggestion of the contribution of work motivation factors, this was linked to the concept of perceived competence.

The sample was divided in to two groups, 5 spouse/partners and 6 sons/daughters. The measures used were a semi-structured interview, standardised questionnaires on carers' difficulties and satisfactions and a standardised mood state questionnaire.

#### 1.9.2 The research questions were:

What factors play a part in the decision to take on and continue in their role of caring for a spouse/partner or parent with dementia?

Quantitative research suggests the most stressful factors for carers to manage are non-cognitive features of dementia, including behavioural problems. Would these results be borne out using qualitative methods to look at the factors carers experience as most difficult to manage or stressful in caring for a family member with dementia?

What are the factors carers find most satisfying or rewarding in caring for a family member with dementia?

What are the factors associated with the carers' perceived competence in the caring role?

Given the evidence from qualitative research on relationship differences, it was predicted that there would be differences between the responses of son/daughter and spouse/partner carers in the perceived stresses and rewards of caring.

## **2. METHOD**

### **2.1 Design**

In order to address the research questions a two part design was employed, following the principle of triangulation (Campbell & Fiske, 1959), in which data is collected from different sources or perspectives on the same phenomena. Qualitative methods were used to explore the subjective perceptions of two groups of participant carers, supplemented by quantitative data on the stresses and satisfactions of caring from a postal survey of a larger clinical sample.

#### **2.1.1. Postal Survey**

A postal survey was used to elicit quantitative data from two standardised questionnaires, the Carers Assessment of Difficulties Index (CADI) (Nolan & Grant, 1992) and the Carers Assessment of Satisfactions Index (CASI) (Nolan & Grant, 1992). The postal survey was linked to the researcher's involvement in a community dementia care project that ran from 1996 to 1998. A carer satisfaction questionnaire was devised which involved mailing all carers who had received a service from the project and who were not excluded by specific criteria, detailed later. Mailings for this took place in June 1997 and August 1998, and the CADI and CASI were included in these mailings. The total number of carers surveyed was 115.

#### **2.1.2. Semi structured interview and mood state questionnaire**

A non experimental cross sectional design was used, with two groups of participants, all of whom were caring for a close family member with dementia. The participants

were primarily a sub-sample of those who had received the postal survey in August 1998, who indicated that they would be willing to be interviewed for the present project. Interviewees also completed the Hospital Anxiety and Depression Scale (HAD) (Zigmond & Snaith, 1983). Verbatim notes were taken of each interview using an informal shorthand technique.

One group of interviewees were spouse/partners (N = 5) and the other adult sons/daughters (N = 6).

## **2.2 Participants**

In quantitative research statistical sampling is used to maximise external validity. Mays & Pope (1995) point out that statistical representativeness is not a prime requirement when the object is to understand social processes, and suggest the use of non-probabilistic sampling is acceptable in these situations. The purpose is to identify specific groups of people who either possess the characteristics or live in circumstances relevant to the social phenomenon being studied, and who will enable exploration of an issue relevant to the research. In the present study, the aim was to identify close family carers of someone with dementia, rather than a 'representative' sample drawn from the population of carers. This was achieved in the following ways:

### **2.2.1 Postal Survey**

The Department of Health provided funding for a community dementia care project within one locality of the local NHS Trust, from April 1996 to March 1998. The aim of the project was to co-ordinate the assessment and provision of appropriate services



for people identified as having dementia and their carers within the locality. It involved input from Social Services and the local Carers' Centre in addition to that from the Trust. The Department of Health funding was for a full-time Project Co-ordinator and a part-time secretary. It was a condition of funding that the project was evaluated, and the carers' satisfaction survey undertaken by the researcher was part of this wider evaluation.

The carers' satisfaction survey was sent by post to all carers who had received a service from the dementia care project and who were not excluded by criteria devised to prevent inappropriate or distressing contact with carers. The exclusion criteria were:

- Client had no carer
- Client had died
- Carer had died
- Carer known to be seriously ill
- Carer had specifically said they did not wish to be contacted
- Client was found not to have dementia following assessment
- Insufficient details on file of either the client or carer.

The mailings of the carers' satisfaction survey took place in June 1997 and August 1998. Included with the questionnaire looking at carer satisfaction with the dementia care project was a covering letter (Appendix 1) asking if people would be willing to complete two further questionnaires, the CADI and the CASI, which were enclosed.

A total of 182 people received a service from the dementia care project, of whom 67 were excluded from the survey by the criteria, leaving 115 who received the postal survey. 72 carers were sent the survey in 1997 and 43 in 1998.

**Table 1 showing characteristics of postal survey participants**

Relationship to care recipient	1997 mailing	1998 mailing	Total
Wife	12	9	21
Husband	14	5	19
Daughter	24	14	38
Son	9	9	18
Other relative	10	1	11
Other	3	5	8

Of the 115 people who received the postal survey, 40 returned the CADI and CASI, giving a total response rate of 35%.

### **2.2.2. Semi-structured interview and mood state questionnaire**

The aim was to recruit 6-8 current carers of a close family member with dementia in each of two groups – spouse/partners and adult child carers. They were recruited via the August 1998 mailing of the carer satisfaction survey described above. A separate sheet outlining the present project was included (Appendix 2), asking any willing participants to return a slip giving their name, address and relationship to the care recipient and giving permission to be contacted. 16 people responded indicating a willingness to be contacted to arrange an interview: 5 spouse/partners, 8 daughters and 3 with more distant or no family relationship to the care recipient. 4 potential participants were excluded at this stage, due to the nature of the relationship (i.e. not a spouse/partner or adult child carer) or because the care recipient had already moved to

residential care. Excluded potential participants were contacted by letter and thanked for their willingness to take part.

The 12 remaining potential participants were contacted by letter, thanking them for agreeing to participate and indicating that the researcher would be in touch to arrange interviews in the near future ( Appendix 3). Following this, 4 potential participants indicated that they could no longer take part, or the researcher took this decision based on the carers' changed circumstances, including death or serious decline in the health of the care recipient and death or serious decline of the identified carer. This left 8 carers who were still willing to be interviewed, 4 daughters and 4 spouse/partners of someone with dementia.

Given the small numbers – it had been hoped to interview 6-8 people in each group – further steps were taken to recruit participants from another local clinical service for carers of someone with dementia. This was an educational group for carers run in an adjacent borough within the same NHS Trust. The group leaders were contacted and given full details of the research. They agreed to discuss it with the group they were currently running and to hand out modified versions of the information sheets and reply slips that had been sent to recipients of the Department of Health funded project (Appendix 4). This resulted in the recruitment of a further 3 participants, 2 daughters and one spouse.

**Table 2 showing recruitment of interviewee participants**

Initial response rate to 1998 mailing (total N = 43)	Number of participants interviewed from 1998 mailing	Response rate from Carers group (total N = 9)	Participants included from the overall sample (N = 52)
16 (37.2%)	8 (18.6%)	3 (33%)	11 (21.1%)

Available demographic information on the 11 interviewee participants is given below:

**Table 3 showing overall characteristics of interviewee participants**

Relationship to care recipient	Number	Co-habiting	Mean duration as carer
Wife/partner	3	3	5 years
Husband/partner	2	2	13 years
Daughter	6	2	3.6 years
Son	0	N/a	N/a

One of the uses of the Hospital Anxiety and Depression scale (HAD)(Zigmond & Snaith 1983) was as a population descriptor. Tables 4 and 5 show each individual's HAD score, along with details of co-habitation and years spent as a carer. The latter was an approximation in cases when carers were unsure.

**Table 4 showing individual participants' HAD scores, details of co-habitation and estimated care duration for spouse/partner carers**

Carer	HAD - anxiety	HAD – depression	Co-habiting	Care duration
GP	8	2	Yes	2 years
ZB	9	6	Yes	1–3 years
TE	8	11	Yes	12 Years
MW	2	3	Yes	14 Years
MS	11	12	Yes	11 Years
	Mean = 7.6	Mean = 6.8		Mean = 8.2 years

Zigmond and Snaith suggested the following scoring system for the HAD:

0-7 = normal range

8-10 = borderline

11 + is indicative of a psychiatric 'case'.

**Table 5 showing individual participants’ HAD scores, details of co-habitation and estimated care duration for adult child carers**

Carer	HAD - anxiety	HAD – depression	Co-habiting	Care duration
EB	5	12	Yes	2 years
ME	2	1	No	1 year
NJ	15	10	Yes	3 years
HS	15	6	Yes	2-5 years
MP	10	6	No	5-6 years
WG	17	10	No	1 year
	Mean = 10.66	Mean = 7.5		Mean = 3.6 years

**2.3 Measures**

**2.3.1 Standardised questionnaires**

**2.3.1.1 The Carers Assessment of Difficulties Index (CADI)** (Nolan & Grant, 1992) is a 30 item questionnaire listing common difficulties carers may face in their day to day caring situation. Respondents indicate the frequency of the problem and the degree of stress it causes. It is not specific to caring for someone with dementia and to allow for areas of difficulty not covered within the 30 items there is space at the end for respondents to add further items (Appendix 5).

**2.3.1.1.1 Reliability and validity of the CADI**

The CADI was devised for an extensive study by Nolan & Grant of a respite bed scheme, which involved interview and survey data from a sample of over 500 carers. Content validity of the CADI was ensured by extensive reference to existing scales and to the empirical and theoretical literature. Factor analysis and causal path analysis of the derived factors were used, resulting in 7 subscales: carer dependant

relationships, reactions to caregiving, physical demands of caring, restricted social life, poor family support, poor professional support and financial consequences. The Cronbach Alpha co-efficient for the CADI is .92.

**2.3.1.2 The Carers Assessment of Satisfaction Index (CASI)** (Nolan & Grant, 1992) is a 30 item questionnaire consisting of statements about potentially satisfying aspects of caring. Each statement allows respondents to indicate the extent to which they find the given aspect satisfying (Appendix 6).

**2.3.1.2.1 Reliability and validity of the CASI**

The CASI was devised for the same study as the CADI. Again, Nolan & Grant drew on existing empirical data, but it should be noted that there was not then (and still is not) very much empirical data on the rewards/satisfactions of caring. The Cronbach Alpha co-efficient for the CASI is .91.

**2.3.1.3 The Hospital Anxiety and Depression Scale (HAD)** (Zigmond & Snaith, 1983) is a 14 item questionnaire assessing mood state. It was devised to detect mood disorders in non psychiatric populations attending other hospital departments and thus avoids inclusion of somatic items (e.g. loss of appetite, insomnia) which are also likely to be present in a person suffering from physical illness. Zigmond and Snaith claim the HAD is particularly user friendly for non-psychiatric populations because none of the items imply a disorder (e.g. reflecting suicidal ideation), and because it is brief.

It was deemed an appropriate measure to use in the present study because of the possible co-existence of physical health and emotional health problems among the participants; the fact that somatic symptoms of depression such as insomnia may also be a result of living with someone who is wakeful or disturbed at night, which is a common problem faced by carers of someone with dementia; and due to its brevity and user-friendliness.

The HAD was used in three ways: firstly, as a population description (see Tables 4 and 5), to enable comparisons with other clinical populations of carers used in the literature; secondly, as a way of obtaining more information about the individual participants and their emotional well-being; and thirdly, to see whether there were any common features apparent among those participants with high scores. The HAD is shown in Appendix 7.

#### **2.3.1.3.1 Reliability and validity of the HAD**

The original measure was standardised on a sample of adults aged 16-65 attending general medical out-patient clinics, however it has since been validated for use with groups over the age of 66 and in a range of medical and non-medical settings (Spinhoven, Ormel, Sloekers, Kempen, Speckens and Van Hemert, 1997).

The original standardisation yielded internal consistency correlations significant at the  $p < 0.01$  and  $p < 0.02$  levels (for anxiety and depression sub scales respectively). The reliability of clinical case decisions (correlating sub-scale scores and independent psychiatric ratings) was significant at  $p < 0.001$  level. Spinhoven et al (1997) found that test-re-test reliability of the total scale and sub-scales were good, but found that



positive predictive value was only moderate. They suggest the HAD is best used as a screening questionnaire rather than a case identifier.

### **2.3.2 Semi-structured interview**

#### **2.3.2.1 Development of the interview questions**

The development of the research questions for the current project, and the subsequent interview schedule, built on earlier work by the researcher, outlined in section 1.9.1. When the researcher undertook the carers' satisfaction survey already described, she also conducted interviews with 12 carers who were recruited from the survey sample. The satisfaction survey and interviews aimed to clarify aspects of the dementia care project which were viewed as particularly helpful/unhelpful; to identify service gaps; to gain an understanding of carers' paths through services and their subjective experience of this; and to assess levels of carer stress and coping. The interview questions included: the first signs of change noticed in the care recipient; the professional from whom help had first been sought; whether or not the care recipient had been informed of their diagnosis, and arguments for and against this; satisfaction with services received by both the carer and care recipient; additional services they would have liked for themselves or the care recipient; and issues around consideration of any future move to residential or nursing care. The interview data from this earlier project was portrayed descriptively, although it was thought that a qualitative approach might yield more detailed and richer data.

The interview questions for the current project were therefore informed by both previous published research in the area of carer stress and the researcher's own prior work.

The pilot interview questions for the current project are given below. Items in brackets indicate follow up questions or prompts.

- Who do you care for?
- How long have you been caring for them?
- Do you live in the same house? (If not, how often do you see X?)
- How did you come to take on the role of caring for X?
- What aspects of caring for X do you feel you manage particularly well?
- Has your sense of competence changed over time? (Do you feel more competent than when you became a carer or less so?)
- What changes in your sense of competence do you expect in the years to come?
- Do you gain any personal satisfaction from caring for X? (What sort of things give you personal satisfaction?)
- What are the things you find most difficult to manage or stressful in your role as carer?
- What, if anything, are the things that help you continue in your role as carer?

**2.3.2.2 Pilot interviews:** the first participant in each group was treated as a pilot interview. At these pilot interviews one carer introduced the concept of frustration. It was therefore decided to change the wording of the penultimate question to

- What are the things you find most difficult to manage, stressful or frustrating in your role as carer?

and to move it to an earlier position in the interview (after the question on how people came to take on the caring role) in order to let participants discuss some of the negative aspects of caring before moving on to any satisfying aspects of caring.

## **2.4 Ethics**

Although the present study did not involve direct contact with any patients of the Trust, these technically being the care recipients rather than the care givers, it was considered vital to subject the project to the Trust's Ethics Committee for approval, and this was done in June 1998. The application was given approval by the Committee. Full details of the application and approval are given in Appendices 8 and 9.

It was specified in the Ethics approval application that if carer participants were identified as being particularly vulnerable or stressed, and in need of further input, they would be encouraged to contact their General Practitioner or permission would be sought for the researcher to liaise with the relevant clinical service to which they were already linked (i.e. the community dementia care service or the carers' group).

## **2.5 Administration**

Having agreed to be contacted to arrange the interview, all participants were offered a choice between being interviewed in their own homes, at the researcher's clinical office, or at an alternative Trust venue – a local day hospital. 7 chose to be interviewed at home, 3 at the researcher's office and 1 at the day hospital.

On meeting, the researcher introduced herself and briefly explained again the focus of the research (the stresses and rewards of caring and their own experience of caring for their relative) and the structure of the meeting. Complete confidentiality was assured.

The participant was then given an information sheet on the research to read and keep (Appendix 10). They were asked to complete a form giving informed consent to the interview and questionnaire, which was counter-signed by the researcher (Appendix 11). They were asked if they would like a summary of the results on completion of the project.

The HAD was administered next, with the researcher reading the items aloud and the participant choosing the preferred response. This form of administration controlled for any differences in literacy skills and was intended to develop rapport with the researcher prior to the interview. It also enabled follow up questions to be asked after administration if appropriate or necessary.

Before commencing the interview, the researcher reiterated her interest in the participant's own experience of caring for their relative. It was explained that the main data to be analysed would consist of their answers to the questions, and that verbatim notes would therefore be taken. It was considered that participants may be less accepting of tape recording than note-taking. The researcher took the notes using an informal shorthand technique employing multiple abbreviations and symbols. On two occasions, when interviewees talked about issues unrelated to the research, note-taking was suspended for the duration of the digression. All participants were told that they could halt the interview at any time if they were feeling unable to continue. The interview was then conducted and the main points summarised on completion. When the interview was finished participants were thanked for their time. For those who had appeared to have particular pressing needs, the researcher sometimes continued to talk about the care they offered their relative and the impact on them. In

two cases this resulted in giving information about further clinical services, and in two others giving advice about management strategies or brief supportive counselling.

## **2.6 Data management**

Interpretative Phenomenological Analysis (IPA) Smith (1996) was used on the qualitative data resulting from the semi-structured interviews. IPA is concerned with the individual's personal perception of an event rather than attempting to produce an objective account (Smith, Jarman and Osborn 1999). However, it acknowledges that access to this must be an interpretative process, involving the researcher's attempts to make sense of the other's world. It was thought that this would be particularly appropriate to the topic of carers' experiences, as it draws on a well-established body of knowledge associated with the Stress Process Model (Pearlin, Mullan, Semple and Skaff, 1990) highlighting the importance of subjective rather than objective dimensions in determining carer stress.

An ideographic case study approach was adopted. Each interview transcript was analysed separately and then the common themes that emerged within each group were identified. In this way it was hoped to minimise the loss of data from the interviews that may have resulted from adopting a group approach to the initial analysis. A detailed description of the way in which IPA was used follows, and was based on Smith, Jarman and Osborn (1999).

Each transcript was read repeatedly, so the researcher could become thoroughly acquainted with the text. Comments were made in the left hand margin – either

summarising, making association, connections or interpretations. In the right hand margin notes were made of any emerging themes - attempts to capture the essence of the text using key words. Having listed the emergent themes on a separate piece of paper, all themes were marked with the page and line of text in which they appeared. This process was repeated for each individual's transcript. The lists of summary themes were then explored for each group, and a 'master' list of group themes was compiled. Smith, Jarman and Osborn suggest selection of master themes can be made on the basis of richness of data and how the theme illuminates other aspects of the account as well as prevalence. Again, all identified themes had details of the points in the transcript which illustrated them.

#### 2.6.1 Reliability and validity of the qualitative study

Clearly issues of reliability and validity are more complex to address in qualitative than in quantitative research. Mays & Pope (1995) suggest that in quantitative and qualitative research the basic strategy to ensure rigour is systematic and self conscious research design, data collection, interpretation and communication. Beyond this, they propose two goals for qualitative researchers: to create an account of method and data which can stand independently, so that another trained researcher could analyse the same data in the same way and come to the same conclusions; and to produce a plausible and coherent explanation for the phenomena under scrutiny.

These goals were operationalised in the present study in a number of ways:

### Triangulation

Good & Watts (1996) highlight triangulation as an important principle of qualitative research. In the present study this was achieved by looking at the stresses and rewards of caring via standardised questionnaires from a larger clinical sample as well as via the semi-structured interviews.

### Auditability

This was achieved by taking a clear, well-documented and systematic approach to the process of collecting and analysing the data. Marshall & Rossman (1989) suggested keeping a research diary, and this was maintained throughout the process (Appendix 12).

### Inter-rater reliability

Mays & Pope (1995) suggest the reliability of analyses can be enhanced by an independent assessment of transcripts by an additional skilled qualitative researcher and comparison of agreement between raters. This was done in two ways. Firstly, four of the transcripts were sent to an experienced second rater, for initial thematic analysis. The results were returned to the researcher and then discussed in detail. Good agreement was found between the two raters, although there were instances in which both raters had identified the same underlying issues in an identified piece of text, but had named them differently. This will be discussed in section 4. Details of the different thematic analyses are given in Appendix 13.

Secondly, the same second rater sorted given excerpts from the text into themes in response to each research question. For each research question, a randomly presented sample of excerpts showing the identified themes were given to the second rater. Her

task was to sort the excerpts into the identified themes. These were returned to the researcher, and Cohen's Kappa co-efficient (Silverman, 1993) was calculated for each question. The full results are given in Appendix 14. In summary, the co-efficients ranged from .71 to 1. The two lowest co-efficients (.71 and .84) were then re-calculated having combined two over-lapping themes in each case to eliminate discrepancies, which increased the co-efficients to .92 and .88 respectively. The percentage agreement between raters ranged from 86% to 100%.

### Theoretical linking

Johnson (1999) states that 'transferability' in qualitative research is equated with external validity in quantitative research – the extent to which findings are generalisable to other populations. She suggests that it should be possible for others to assess how the data link with a body of theory, but the onus is on the researcher to relate the findings to a theoretical framework and a body of empirical work. This is done in the discussion section of the present study.

### Minimising researcher bias

Good & Watts (1996) advise qualitative researchers to take special care to consider their personal connection to what is being studied. They claim the 'ideal' is for the researcher to be sufficiently in tune with the culture to understand the nuances of psychological transactions, while regard for impartiality and commitment to validity remain unclouded. A statement of the researcher's background and interest in the subject under investigation is included in Appendix 15. Furthermore, Mays & Pope (1995) stress the importance of presenting the research in such a way that the reader can clearly distinguish between the data and the interpretation. In the present study



this was achieved by presenting the themes ( the interpretation) with relevant data given as examples of these and quoted verbatim in the text of the results section. Mays & Pope also suggested that a full transcript of the raw data should be made available if feasible, and all the transcripts are given in Appendices 16-26. All identifying material in the transcripts has been changed to preserve confidentiality.

### **3. RESULTS**

#### **3.1 Thematic analysis of qualitative data**

The qualitative data were analysed thematically using the IPA methodology described in Section 2.6. The results are given in the form of tables, showing the main themes and sub themes that emerged from this analysis. The data for the two groups are shown separately and relate to the most frequent and richest themes to emerge from the data.

**Table 6 showing the main themes and sub themes to emerge from the analyses of the spouse/partner group.**

Main themes	Sub themes
Care recipient	Dementia: Onset Behavioural manifestations Insight Physical health Loss and change Social contacts/support
Carer	Coping: Strategies Managing behaviour Limitations Adapting to changes Physical and practical impact of caring Emotional impact of caring/illness Social support Models of care Self concept and competence The future
The relationship between the carer and the care recipient	
Services	Those received Shortcomings

Due to lack of space and repetition with section 3.3, the full descriptors of the themes and sub-themes identified in Table 6 are given in Appendix 27.

**Table 7 showing the main themes and sub themes to emerge from the analyses of the adult child carers group.**

Main themes	Sub themes
Care recipient	Dementia: <ul style="list-style-type: none"> <li>Onset</li> <li>Behavioural manifestations</li> <li>Loss and change</li> </ul> Continuity/personality
Carer	Coping: <ul style="list-style-type: none"> <li>Strategies</li> <li>Understanding behaviour</li> <li>Managing behaviour</li> </ul> Caring: <ul style="list-style-type: none"> <li>Emotional impact</li> <li>Physical and practical impact</li> <li>Limits of care</li> <li>Not knowing what it would be like</li> <li>Lack of choice</li> </ul> Physical health Positive aspects Self: <ul style="list-style-type: none"> <li>Self concept</li> <li>Competence</li> <li>Values and beliefs</li> </ul>
The relationship between the carer and the care recipient	Changes <ul style="list-style-type: none"> <li>Roles and responsibilities</li> <li>Reciprocity</li> </ul>
Services	
Family	

Due to restrictions of space the full descriptors of the themes and sub-themes identified in Table 7 are in Appendix 27.

### **3.2 Commentary**

Having completed the individual IPA analyses and grouped the emergent themes as described in Tables 6 and 7, it was apparent that this would not allow a systematic analysis of the research questions. Therefore, the analysis was extended to a third stage, in which the original data – the interview transcripts – were analysed again using the same IPA method in relation to each research question in turn. The results of this analysis are primarily descriptive and follow. Further interpretations of the data are in the discussion section.

### **3.3 Extended results section – qualitative data**

The results are presented separately for each research question. Qualitative data is summarised in the form of tables, giving themes relating to each question. The text includes verbatim quotes from the participants' transcripts to illustrate the themes already identified, and these quotes are marked by numbers giving the page and line number in each individual's transcript where the extract can be found. Any identifying details in the text have been changed to ensure confidentiality.

**3.3.1 What are the factors that play a part in the decision to take on and continue the role of caring for a spouse/partner or parent with dementia?**

**Table 8 showing the factors that play a part in the decision to take on caring for a spouse/partner or parent with dementia**

Participant group	Themes
Spouse/partner carers	The care recipient's need Their perceived marital role
Adult child carers	Keeping care in the family Not knowing what it would be like

**3.3.1.1 Spouse/partners**

Table 8 shows the themes that emerged for this group, which are detailed below.

**The needs of the care recipient**

Many carers outlined the deterioration in their spouse's health or abilities that led to a perception of need for care. GP, a wife carer, specified that she had been caring only 'Since it became obvious he was suffering with dementia' (1.4) despite her husband's chronic physical health problems, which preceeded the onset of dementia. MW, a male carer, identified more practical changes in his partner's abilities 'Until (the accident) she was okay, working, cooking meals. She can't cook a meal now' (1.10).

**Their perceived marital role**

This theme related to the apparent acceptance that it was a natural and integral part of the marital role to take on care, and was illustrated by the two male participants in the group. Thus TE commented 'It's automatic isn't it? I'm her husband, and as we found out about her forgetfulness and Alzheimers then I took on the things she

couldn't do. It's like an automatic switch over' (1.22). And MW commented '...it's the same as bringing up the kids or anything. I just fell in to the role and do it...Looking after always came natural like' (1.24).

### **3.3.1.2 Adult child carers**

Table 8 shows the themes that emerged for this group, which are detailed below.

#### **Keeping it in the family**

This was a major theme for adult child carers, with an implicit or explicit assumption that care would be provided within the family, although not all families agreed on the limits to this commitment. This theme incorporated comments relating to the carers' commitment to the family, and the role of work commitments and geography in deciding who within the family would take on the role of carer.

Commitment to the family: HS, who had lived in the family home all her life and had cared for her father as well as her mother, said 'Living here, I just naturally...you just naturally do it. This is my family home' (1.13). EB explained her sister in the USA '...couldn't cope anymore, but we didn't want to put her in a Home, so I said I would do it' (1.11). PM gave a longer explanation 'I laugh because it sounds implausible, but that's how it happened. When I was eight my father went to war, and my sister was two. And he looked me straight in the eye and said 'Take care of your mother' and I have always taken that on. In reality not, because my father returned from war, and didn't die till 1979, and my mother has been more dependent on my sister and myself since then' (2.5).

Work commitments: WG, commenting on how she took on her father’s care, said ‘It’s the usual thing. I’ve got two sisters, but I’m the only one who works part time. I get the impression their full time jobs are more important than their father’ (1.15).

Geography: ME said ‘There’s just my sister and I. She lives in Hampshire, so it’s more difficult for her’ (1.15) and ‘It was just the luck of the draw that I happened to be nearby’ (1.17).

Not knowing what it would be like

Two daughter carers expressed a view that they would not have taken on the role of carer if they had realised that their parent had dementia, or what the caring would be like. NJ commented ‘If I’d known what he was like I’d have had him in a Home’ (1.21) and ‘It (care) was more or less forced upon me by circumstances and the law’ (1.25).

**Table 9 showing the factors that play a part in the decision to continue caring for a spouse/partner or parent with dementia**

Participant group	Themes
Spouse/partner carers	The relationship with the care recipient Support from others
Adult child carers	The relationship with the care recipient Support from others Lack of choice



### **3.3.1.3 Spouse/partners**

Table 9 shows the themes that emerged and details are given below.

#### **Relationship with the care recipient**

Included within this were comments denoting a wish to continue caring at home, notions of reciprocity and expressions of love. Comments about satisfying aspects of caring for their partners are in section 3.3.3.1 but also relate to motivations for continuing to care.

Caring at home: GP said ‘...I want my husband to be able to go on and to be at home’ (3.3). MS said ‘I wouldn’t want him to go into a Home or anything’ (3.1).

Reciprocity: TE said ‘...it’s an automatic thing. She’s looked after me in her time and now I look after her’ (2.34).

Love: MS said ‘Because I love him so much. I wouldn’t want him to go anywhere else and I know he wouldn’t have wanted that. I love him too much for that’ (3.16).

#### **Support from others**

One carer specifically mentioned her family in this context and one mentioned the carers’ group she had joined. GP said ‘First of all, I have a good family and they are very supportive’(3.3). ZB said ‘...it was going to the carers’ group. It opened your eyes to the problem and you know it’s not their fault. And just the fact that if I need help there’ll be help’ (2.16).

### **3.3.1.4 Adult child carers**

Table 9 shows the themes that emerged and details are given below.

#### **The relationship with the care recipient**

This theme incorporated notions of duty, empathy and the care recipient's happiness with their carer, as well as affectional ties.

For example, MP said 'Well, something helps me continue, 'cos I do. Undoubtedly one of the things is duty. And...she's my mother. I don't love her, but I like her better than I used to, so I think that helps. I feel for her. I dare not get in touch with what it must be like for her...it must be so confusing and frightening to be in her head...(4.22)...But the knowledge that it is difficult is one of the things that keeps me going. I know it's hard for her and I want to do what I can' (4.28).

HS said 'Well, because she's pleased. She's glad I'm here looking after her and that' (2.20).

#### **Support from others**

ME commented 'The fact that my sister shares with me' (2.26). And WG said 'Basically, I'm a Christian, and I know there are people praying for me, and I find that very comforting...(3.13)...And it's a help that my sister rings me now...(2.16)...And the biggest help is my husband. I couldn't manage without him' (3.17).

#### **Lack of choice**

EB said '...I have to I suppose, because there's no-one else to do it' (2.16). And ME said '...there isn't anyone else if I don't do it – lack of choice' (2.26). In one way this

demonstrates the extent of opposition to institutional care as an alternative to family care.

**3.3.2 What are the factors carers experience as most difficult to manage or stressful in caring for a family member with dementia?**

**Table 10 showing the main stressors/difficulties for spouse/partners and adult child carers.**

Participant group	Themes
Spouse/partner carers	Emotional aspects Behavioural aspects Limitations
Adult child carers	Emotional aspects Behavioural aspects Limitations Personality and relationship factors

**3.3.2.1 Spouse/partners**

Table 10 shows the themes that emerged and details are given below.

**Emotional aspects**

This theme included the emotional impact on both the carer and the care recipient of the situation and incorporated issues of loss and change. In relation to the care recipient’s emotional reactions to knowledge of their condition, ZB said ‘The most difficult thing is cheering him up. He gets terrible depressions. He’s very aware of what’s happening to him’ (1.13).

Referring to his own stress TE said ‘The frustration and stress are the worst things and it’s a long period of time’ (3.3). (TE had been caring for 14 years.) MS said ‘I think

the hardest thing is when they don't want your help. You say 'I'm only trying to help you' and they say 'I don't need your help'. But they do. That's very hurtful' (3.22).

TE spoke of the stresses of change and loss 'There are times when I'd like to strangle her...It's the sheer frustration of...the role changes...in the early days you can't believe such a lively person can change. You just can't believe it, even when you know it' (2.35). MS said 'We've always been so close, it's knowing he's going this way that's the upsetting part' (3.8).

### Behavioural aspects

Although most of the carers of both groups mentioned a number of changes in the care recipient's behaviour often found in people with a dementia, these were not strongly highlighted by spouse/partners in response to a direct question about their main stresses/difficulties in caring. The ones that were mentioned seemed to relate to the emotional meaning to the carers of resistance and lack of appreciation of their care. GP, whose husband is incontinent, said of this 'I will have to get in touch with the male nurse to get him to talk to my husband. He's almost trying to deny that he has a problem and has been a bit lax. If he would just accept it and make the best of it...' (2.31) and later 'I just can't talk to him about it (the incontinence). He gets a little bit upset and angry and throws things around a bit, and I can't cope with this as well as everything' (3.12). MS commented on her husband's apparent resistance to care, saying 'He doesn't want to do what I ask him to do – he seems very defiant' (1.32) going on to talk about the effects of his memory impairment 'I try to ...go along with him, but you can't all the time...He says he wants to look for Maddy – that's me – and if I tell him I'm Maddy he says 'no you're not, you're my sister' and half an hour later he'll remember I am his wife' (1.34).

### Limitations/restrictions

The limitations included within this theme related to time, getting out (either socially or to do practical things like shopping) and interests/activities.

GP said 'I don't resent it, but I can't really get on with the things I'm interested in' (2.24) and 'I've always enjoyed studying languages... I'd love to continue but there's no time, and when there is you are too tired' (2.27). TE thought 'The most stressful thing is being a prisoner in your own home' (1.28).

### **3.3.2.2 Adult child carers**

Table 10 shows the themes that emerged and details are given below.

### Emotional aspects

EB said 'I also feel a lot of anger and irritability and then I feel guilty if I shout at mum for asking the same questions again and again' (2.28). ME said 'There's no way of approaching her – it's like we're on two different wavelengths' (1.22) and later 'I'm still hurt that she accused me of taking things from the home – there is a lot of anger there' (2.2). MP said 'I find it stressful to spend much time with my mother now, so I do it in short bursts' (2.22).

### Behavioural aspects

In some instances these reflected the care recipient's memory problems, while some others referred to their incontinence and their perception of problems.

For example, ME thought the most difficult thing was 'Trying to persuade her that certain ways of doing things would be to her benefit – hygiene, safety in the home – a

spectrum of things... She agrees and then it reverts back' (1.23). MP said 'I think the most difficult things are to do with bodily functions...eating or not eating. She's incontinent now and is beginning to be doubly incontinent and I find that very difficult' (2.20). WG thought the most difficult thing to manage was '...the phone calls...He's always got a problem that isn't a problem' (2.35).

### Limitations/restrictions

There were extensive practical restrictions for many carers, which some highlighted in response to this question. For example EB talked about 'The fact that I have to do things every day, like getting up early in the morning, even if I feel like lying on... The limits on my time' (2.11). NJ thought the most difficult things to manage were 'The lack of freedom. We can't have a holiday or go away or any of those normal things' (1.28).

### Personality and relationship factors

This theme related to pre-existing personality and relationship factors that were difficult for the carers to manage. For example, ME had identified trying to persuade her mother to do things a certain way as the most difficult thing to manage. When asked whether this represented a change in her mother she replied 'No, it's part of her personality. She has always liked to be in control and is quite stubborn' (1.25) and later 'she senses a deterioration in the relationship...she was very supportive when I was younger, and I owe her a lot, but I do feel very hostile and it surfaces in conversation' (2.5).

NJ talked about lack of freedom as the most difficult thing, 'and also my father's personality, regardless of the dementia' (1.20) and later 'He doesn't go to the day care

or respite because he’s got a very bad temper – he’s a very difficult man, my father...’  
(1.33).

**3.3.3 What are the factors carers find most rewarding or satisfying in caring for a family member with dementia?**

There was some duplication between aspects of the situation carers found satisfying and those that helped them continue to provide care. The themes and raw data shown below only relate to responses to the above question.

**Table 11 showing the main rewards for spouse/partners and adult child carers.**

Participant group	Themes
Spouse/partner carers	Emotional/relationship Normality/continuity
Adult child carers	Emotional/relationship Self perception

**3.3.3.1 Spouse/partners**

Table 11 shows the themes that emerged and details are given below.

**Emotional/relationship**

When asked about any personal satisfaction gained from caring for his wife, TE replied ‘Only when she smiles. That’s the only way I know she’s alright. Nothing else’ (2.30).

**Normality/continuity**

Some carers mentioned aspects of the situation that denoted life carrying on as before: for example, GP said ‘I’m sure I do, yes, yes...just the fact that we’re getting along,

and I see that he is reasonably healthy. He goes out when it's nice weather...' (2.10). And MS said 'Oh yes. I wouldn't want him to go into a Home or anything...I can care for him alright... We've always been so close... We've always done everything together' (3.1). Although this clearly denotes opposition to institutional care, it seemed the fact that MS and her husband were in this situation together, as they had been in the rest of their marriage, was an important factor for her.

**3.3.3.2 Adult child carers**

Table 11 shows the details that emerged and details are given below.

Emotional/relationship

While MP initially expressed the view that she did not get much satisfaction from caring for her mother, she went on to describe a number of things that did give her a sense of satisfaction, such as jointly participating in activities that her mother enjoyed. She went on to describe a big party she had organised for her mother's 90<sup>th</sup> birthday, how well attended this had been and how everyone in the family had contributed a song, tune or poem, finishing 'When I went to see her the next day she said "What you did yesterday, it was good." And do you know, that's the first time she's ever said that. It was a great party' (4.17). Being appreciated was also a feature for WG, who talked about two aspects of caring she found particularly satisfying, her father's appreciation of her care, and her ability to boost his self esteem. She described them: 'When he says things like "I hope I'll be coming to you for Sunday dinner, 'cos you make a lovely dinner." He's always thanking me...' (4.3) and 'I can boost him up sometimes...I think he relies on me praising him. I can build his confidence...' (4.6).



Self perception

The way in which carers viewed what they did positively was mentioned by some. For example, NJ said ‘I suppose I feel I’m doing a good job... It makes me feel grown up, looking after a parent’ (2.25). HS said ‘I’m satisfied with what I do...’ (2.16). And WG said ‘...I’ve learnt I can help other people in the same position, like I come here (to a carers’ group) to help out. That gives me a lot of satisfaction’ (2.35).

3.3.4 What are the factors carers associate with their perceived competence?

**Table 12 showing the main factors associated with carer competence by spouse/partner and adult child carers.**

Participant group	Themes
Spouse/partner carers	Physical and practical care Self concept
Adult child carers	Emotional care Physical care Practical care Self concept

**3.3.4.1 Spouse/partner carers**

Table 12 shows the themes that emerged and details are given below.

Physical and practical care

GP thought she managed ‘All the physical things’ (1.27) well, and when asked if her competence had changed over time said ‘Yes, it has. It has to. I am the one who has to see to everything. I have become a bit of a business woman’ (2.1). TE linked his competence to his ability to keep ‘in charge’ (2.22) and to manage the gradual changes in routine consequent upon his wife’s deteriorating condition.

ZB said 'I suppose I've become more competent through sheer necessity' (1.27), saying 'I have to make more decisions now. The post comes in all the time and you have to make your own decisions. There's no point saying "what do you think of this?"' (2.1).

### Self concept

GP said '...I've taken over. I've surprised myself at times' (2.2) and ZB said '...there's a sense of satisfaction in knowing I'm capable' (2.13). MW said 'If you'd asked me years ago when it started like this, it was a bit of a job to know if you could do these things or not. I think once you accept what she's got, everything comes natural to you' (1.28).

#### **3.3.4.2 Adult child carers**

Table 12 shows the themes that emerged and details are given below.

### Emotional care

When asked what aspects of caring she thought she managed particularly well, ME said '...I think just the contact. She tells me how much it means to her and I know it brings her a lot of pleasure' (1.34). MP said 'I think I'm able to provide boundaries and structures for her. When she gets paranoid or..umm..obsessional about things, I think I'm able to talk to her about it and make it less powerful...I think that's what I do best...I think she trusts me even in her confusion' (2.36).

### Physical care

EB said of her mother 'I think she's utterly spoilt. She is well fed and clothed, warm and comfortable...' (1.23) and in relation to her competence 'My tolerance and

patience have become a lot worse. I think I'm doing just as well' (1.28), thus drawing a distinction between emotional aspects of care and overall competence.

### Practical care

ME thought her sense of competence had increased '...because not only do I work and run my own home, I do a lot for her too – juggling her hospital appointments, paying her bills, her medication, changing arrangements for Meals on Wheels etcetera...She cared for me and the roles are reversed now' (2.10). NJ thought she managed well '...the housewifey bit, cooking, cleaning the home and that sort of thing' (2.5). In relation to her competence she said '...in some ways it's better, because I've had to cope with things I hadn't done before...' (2.12).

### Self concept

A number of the adult child carers mentioned how they would not have anticipated being able to manage all that they had done in relation to caring. For example, ME, having run through all she does for her father said 'Five years ago I would have thought "I can't do all that!"' (2.13). And WG said she had '...learnt to be more competent. At the outset you can't believe you'll be able to cope with all this' (2.20).

## 3.4 results of quantitative data

### **3.4.1 The HAD**

The results of the HAD were given in Tables 4 and 5, showing the scores for each participant. These indicated that 3 carers had levels of depression that reached clinical levels on the HAD and 4 had clinical levels of anxiety.

Looking at participants with extreme HAD scores, there did not appear to be any obvious commonalities, such as type of relationship, time spent caring, or whether or not the carer co-habited with their dependant.

### **3.4.2 The CADI**

The results of the CADI were obtained from the postal survey and were used to address the research question: What do carers find most difficult to manage or stressful in caring for a family member with dementia?

As already described, the CADI asks respondents to indicate whether each item applies to them (i.e. problem occurrence), if so how frequently, and to give a stressfulness rating of either very stressed, moderately stressed, or not stressed. There were 40 questionnaires returned, some of which had not had all sections completed; however, no responses were discarded since it was assumed that carers had given valid answers to the parts they had completed, which may have been the most pertinent to them.

The research question was addressed in two ways – by totalling the number of respondents who had chosen the ‘very stressed’ rating for each item, and by totalling the numbers using the ‘very stressed’ or ‘moderately stressed’ rating for each item.

The results are given below.

**Table 13 showing CADI items scoring the most ‘very stressed’ ratings**

Item	Number of respondents
The person I care for can play me up	11
I don’t have enough private time for myself	11
It is physically tiring	11
I can’t relax because of worry about caring	9
My sleep is affected	9
It restricts my social life/outside interests	8
I can’t have a break or take a holiday	8
I feel angry about the situation	8
It can put a strain on family relationships	8

In terms of the sub-scales of the CADI, four of the items in Table 13 are from the Reactions to care –giving sub-scale, two from the Physical demands of caring sub-scale, two from the Restricted social life sub-scale and one from the Carer-dependant relationship sub-scale.

**Table 14 showing CADI items scoring highest on combined ‘very stressed’ and ‘moderately stressed’ ratings**

Item	Number of respondents
I don’t have enough private time for myself	30
I can’t relax because of worry about caring	25
The person I care for can play me up	23
I feel angry about the situation	23
The behaviour of the person I care for is a problem	21
My emotional well-being suffers	21
It is physically tiring	21
My sleep is affected	20
I can’t have a break or take a holiday	20

Of the items in Table 14, four are from the Reactions to care-giving sub-scale, two from the Physical demands of caring sub-scale, two from the Carer-dependant relationship sub-scale, and one from the Restricted social life sub-scale.

There is an opportunity at the end of the questionnaire for carers to put down any other difficulties they may find particularly stressful and give it a stress rating. The following difficulties were identified in this way:

Won't answer when 'switched off' – rated moderately stressful.

My mother can't come to terms with her situation – rated very stressful.

Aggressive/domineering – rated very stressful.

I worry about how bad the dementia will become – rated moderately stressful.

Would the family help as carers if I was ill? – rated moderately stressful.

My wife gets out of bed at night – rated moderately stressful.

Needs feeding assistance – rated moderately stressful.

Chews her tongue – rated moderately stressful.

I get tearful and upset – rated very stressful.

Family make excuses not to look after person – rated very stressful.

Full details of the results of the CADI are given in Appendix 28.

### **3.4.3. The CASI**

The results of the CASI were from the postal survey and were used to address the research question: What are the factors carers find most rewarding or satisfying in caring for a family member with dementia?

The CASI is structured so that carers can say if an item applies to them and indicate whether it gives them 'a great deal of satisfaction', 'quite a lot of satisfaction' or 'no real satisfaction'. The research question was addressed in two ways: by calculating

the items most frequently rated as giving a great deal of satisfaction, and by totalling the responses to the ratings a great deal of satisfaction and quite a lot of satisfaction for each item. The total number of questionnaires was 40, of which some were not fully completed. As with the CADI, it was assumed that the responses given were valid and related to the items most pertinent to those carers. The results are given below.

**Table 15 showing the CASI items most frequently rated as providing a great deal of satisfaction**

Item	Number of respondents
Maintaining the dignity of the person I care for is important to me	29
I get pleasure from seeing the person I care for happy	28
It is nice to see the person I care for clean, comfortable and well turned out	27
At the end of the day I know I will have done the best I could	26
Caring is one way of expressing my love for the person I care for	26
I am able to keep the person I care for out of an institution	23
I am able to ensure that the person I care for has their needs attended to	21
I feel that if the situation were reversed, the person I care for would do the same for me	20
It's good to help the person I care for overcome difficulties and problems	20
It is nice when something I do gives the person I care for pleasure	19

Full details of the results of the CASI are given in Appendix 29

**Table 16 showing CASI items scoring highest on combined ratings of ‘a great deal of satisfaction’ and ‘quite a lot of satisfaction’**

Items	Number of respondents
Maintaining the dignity of the person I care for is important to me	35
At the end of the day, I know I will have done the best I could	33
I am able to ensure that the person I care for has their needs attended to	33
I get pleasure from seeing the person I care for happy	33
It is nice to see the person I care for clean, comfortable and well turned out	33
It is nice when something I do gives the person I care for pleasure	32
Caring is one way of expressing my love for the person I care for	30
I am able to keep the person I care for out of an institution	30
It is good to help the person I care for overcome difficulties and problems	28



## **4. DISCUSSION**

This section will look critically at the methodology of the research, the results obtained, including theoretical perspectives for understanding them, and the conclusions and implications for further research.

### **4.1 Methodology**

#### **4.1.1 The design**

A number of improvements could have been made to the design of the project. Given the evidence from empirical studies of gender differences in the ways people cope with and construe the process of caring for someone with dementia, it would have provided another dimension to the research to have been able to explore the gender issue systematically. This could have been done by having four contrasting groups rather than two – sons, daughters, husbands and wives – although this would have presented problems with recruitment, the researcher's time, and space to convey and discuss the results.

Triangulation could have been used differently by administering the CADI and CASI to all the participants as part of the interviews. Thus for each participant there would have been qualitative and quantitative data looking at some of the same issues. By the time this was considered, the second postal survey had already been sent, including both the CADI and CASI and the request for participants for the current project. Thus participants would probably have already completed the questionnaires as part of their response to the survey, in which anonymity was assured. However, conversely it was

helpful to have quantitative data from a much larger sample, which added weight and increased the generalisability of the results obtained.

#### 4.1.2 The participants

The main feature of the participants were that they were recruited from clinical services, which poses the question as to how generalisable the results may be to non-clinical populations. However, there would have been serious problems in using a non-clinical group. Access could have been difficult, but more problematic is the possibility that the people for whom they cared may not have been properly assessed and diagnosed with dementia, and the carers would by definition not have been in contact with clinical services, which provided an ethical safeguard for participants in the project. If the researcher was concerned about any aspect of information shared by participants in the project, she could either address it directly with them, indicate where they could obtain any further information that might be helpful to them, or encourage them to seek additional help from the service with which they were already in contact. Even in the event that a participant did not choose to seek further input from their clinical service, the fact that they were part of that service provided a 'safety net' for them and ensured professional contact would be made with them at some stage. A further question raised by the use of a clinical sample is whether this led to a lower representation of people who find aspects of caring positive.

As has already been mentioned, it would have been helpful to have recruited more male participants. It would seem male carers are proportionately less likely to participate in interviews than female carers, which could be due to the gender differences in coping styles. Participation may reflect a coping strategy of seeking

support, understanding or advice, and wishing to make sense of their experiences. Women may be more likely to employ these means of coping, given Briscoe's (1982) findings on gender differences in emotional expressivity.

#### **4.1.3 The measures**

This section will look at the semi-structured interview and the quantitative questionnaires used in the study – the HAD, the CADI and the CASI.

##### **4.1.3.1 The semi-structured interview.**

The researcher had been interested in exploring issues around perceived competence, but did not think this was fully covered in the interviews. A more useful approach might be to devise a measure of perceived competence specifically for carers of someone with dementia.

##### **4.1.3.2 The HAD**

The advantage of using the HAD was that it provided a brief and user-friendly way of assessing anxiety and depression in the clinical sample. Given the results, indicating higher levels of anxiety than expected, it was useful to obtain a mood assessment covering both depression and anxiety. However, another option would have been to use the short form of the General Health Questionnaire (Goldberg, 1978), which has been used in a number of other studies, so would have enabled better comparisons to be made with other clinical samples.

#### 4.1.3.3 The CADI

There was sufficient information on the development of the CADI to be reassured as to its reliability and validity. The main criticism of its use in this study is that it was not devised specifically for people caring for someone with dementia, but for a wider population of carers. The CADI has since been superseded by a measure called the Behavioural and Instrumental Stressors in Dementia scale (BISID) (Keady and Nolan, 1996), which is aimed at this population of carers and which draws on Nolan's work on the CADI. At the time the postal survey was planned, this measure was not yet published. Some of the postal survey respondents made use of the facility at the end of the questionnaire to include some of the difficulties they found particularly stressful, and these are in the results section. The comments tended to relate to behavioural problems associated with dementia, so helped to address the problem of a non-dementia specific measure.

#### 4.1.3.4 The CASI

There was less information available about the development of the CASI than the CADI, but in the absence of other measures looking at potential rewarding or satisfying aspects of caring it was deemed worth using. This is still an under-researched area and further work is necessary to ensure that the CASI is the best way to measure this aspect of caring.

#### 4.1.4 Administration

The main issue to arise in relation to the administration of the measures, was the decision not to use a tape to record the interviews. Although this would have

provided a more reliable method of transcribing the interviews, the researcher was reluctant to take any steps that might have an inhibiting effect on the participants. It is a moot point as to which is the most off-putting - being taped or having someone write as you talk. During some of the interviews the researcher would have liked to be free to 'engage' more with the participants, for example by making more eye contact, and in retrospect it would have been better to make the method of administration part of the piloting procedure.

There is still a stage of the administration to be completed, which is the feedback of results to participants. All participants indicated that they would like to receive this, and a summary report will be written and sent to them after submission of the main report.

#### 4.1.5 Data management

The interpretative phenomenological analysis approach was thought to be particularly appropriate as a way of exploring the subjective aspects of the caring experience, which research has demonstrated to be the main predictor of the effects of caring. However, using the method exactly as described by Smith, Jarman and Osborn (1999) did not permit the research questions to be systematically answered, and the analysis had to be taken to a further stage to enable this to be done. Because this later analysis used the same method of identifying emergent themes from the raw data it was considered to be consistent with the IPA approach, but it could be argued that the researcher moved towards content analysis at this stage.

Analysing and recording the data was laborious and time consuming, and relaying the results was a wordy process. The researcher was particularly doubtful about the 'labelling' stage, when themes and sub-themes that emerged from the data were grouped and named. This would appear to be the most 'interpretative' part of the IPA method, and the researcher was conscious that attaching a label is a subjective action. The same underlying construct (or theme) may be identified by different raters, but then labelled differently. Also a label that is quite clear and self-explanatory to one person may mean something different again to another. In an attempt to control for this, the researcher tried to give 'objective' descriptors only, rather than interpreting the themes, but this is, perhaps, an unsatisfactory middle-ground between buying in to the qualitative paradigm while still retaining the principles of 'objective' quantitative methodology. It was reassuring to have good inter-rater reliability, although there did appear to be some differences in the labelling process when the underlying concepts were identified as the same. Similarly, the second rater's sorting of excerpts from the transcripts into given categories relating to the research questions resulted in Kappa co-efficients ranging from .87 to 1, which were considered good. (This latter procedure led to two changes in the categories, when there appeared to be overlap between them; the confusing categories were combined in each case.)

A further check on the validity of the data would have been to use respondent validity, in which participants are either given their own raw data or a processed version of the individual or group data to comment on. This was not done for a number of reasons. The first was practical: the researcher experienced distressing life events in the course of data collection, which meant the process took considerably longer than planned. Because none of the data were analysed until all of it was collected, it was

not possible to contact the participants with results until well after their interviews. Several of the participants had experienced crises in the subsequent time (which were learned about through clinical discussions in the community mental health team), and the researcher (a) did not want to bother them at a difficult time and (b) was aware that they may have 'moved on' in their care-giving career in such a way that it would have been hard for them to relate to the interview. Furthermore, it was unclear whether those carers who had received additional input from the researcher after the interview would also have 'moved on' psychologically. There was some evidence of this when a CPN colleague passed on news of one of the participants some time after the interview, saying the participant had found it very helpful to talk to the researcher and saw the relationship with her mother differently as a result. Although ideally an attempt would have been made to obtain respondent validity, in the circumstances described it was considered that this would be of questionable use.

A final criticism of the IPA method as used is to state the obvious – it is a reductionist method, and as such it is difficult to adequately convey the experience of individuals within the groups. The lives of people caring for someone with dementia, especially in the moderate to severe stages of cognitive impairment, are so shaped by the experience, that it is disappointing to feel unable to fully convey the richness of the individual's experience. Using qualitative methods involves getting closer to the participants than one would by administering standard measures, resulting in a greater sense of responsibility to use the information well.

## **4.2 Discussion of the obtained results**

This section will summarise the results of the qualitative and quantitative data in relation to each of the research questions, compare the results with that obtained from other studies, examine how they fit with existing theories of caring, and consider the clinical implications.

### **4.2.1 Summary of results in relation to the research questions**

#### **4.2.1.1 What factors play a part in the decision to take on and continue in the role of caring for a spouse/partner or parent with dementia?**

Spouse/partners tended to respond in terms of a growing awareness of the need to care, and a sense that this was part of their marital role. However, adult child carers tended to focus on issues arising from an assumption that the family should provide the necessary care. For example, who was in a position to offer care? Who was prepared to take this on? A significant minority of this group indicated that their decision was made in ignorance of the facts. These carers also indicated lack of choice was the main reason they continued to care, while other adult child carers highlighted the nature of the relationship with their dependant and the support they received from others. Similar reasons for continuing to care were given by spouse/partners, although none expressed the view explicitly that they had no choice.



Most carers had not decided to take on the role, but found it had evolved, following a period of gradual decline in their dependant, which in many cases had only become clear in retrospect.

#### 4.2.1.2 What are the factors carers experience as most difficult to manage or stressful in caring for a family member with dementia?

Empirical research suggested carers find the non-cognitive features of dementia particularly stressful, including behavioural difficulties in their dependant. In this study, while behavioural problems were mentioned by a number of spouse/partner carers, these tended to relate to their impact emotionally or on the relationship with their dependant. The instances in which the behaviour was the problem tended to concern memory-related difficulties in both groups (e.g. forgetting how things should be done, disorientation, or seeking reassurance repeatedly). Incontinence was another challenging behaviour in its own right for some carers, but was only mentioned in this context by adult child carers, not spouses.

The restrictions imposed on the carers' ability to go out and on their time generally was another source of stress. For some daughter carers there were conflicting demands from other family responsibilities.

The emotional aspects of the situation were stressful for both groups, and for the spouse/partners incorporated a strong sense of loss and change in their relationship and in their sense of the person they had known before. Although this was also a factor for adult child carers it was less prominent in their responses. For this group issues around pre-existing personality or relationship factors with their dependant

were more commonly raised. This could reflect that people choose their partners but not their parents, and that the nature of the pre-morbid relationship is an understandably important determinant of the post-morbid one.

The results of the survey data were consistent with the qualitative findings, and suggested that many of the most stressful items were related to emotional and practical consequences of care giving, such as not having enough private time, being unable to relax, or feeling angry, rather than to particular behavioural problems (although it is important to bear in mind that the CADI was not devised specifically for people caring for someone with dementia). A sense that their dependant could 'play up' was deemed highly stressful, and perhaps implies an impact on the relationship above that suggested by the lower-rated item about the dependant's 'problem behaviour'.

#### 4.2.1.3 What are the factors carers find most rewarding or satisfying in caring for a family member with dementia?

The interviews suggested both groups found aspects of the relationship with their dependant and the emotional benefits of care rewarding. For spouse/partners there was an additional theme of satisfaction that life could continue as before in some important respects, either to do with maintaining a normal 'pattern' to life (interests, social contacts), or that their spouse could still live at home. The investment some carers had in this was clear. In the CASI survey results this was also rated as satisfying, but it is possible that the location of care and the nature of people's commitments both contribute to its importance for carers. There was an underlying sense that both spouses and adult child carers had an implicit notion of what was 'right and proper' in the relationship with their dependant, and that fulfilling this was

a more powerful factor than 'duty,' cutting across some of the identified themes, such as self concept.

The results of the survey data showed that maintaining the dignity of their dependant was the most highly rated satisfying aspect of caring, although interestingly this was not identified as a theme in the qualitative interviews. Other particularly satisfying items related to seeing the dependant happy and well turned out, knowing the carer had done their best, giving pleasure to their dependant and caring as an expression of love. The number of respondents from the total indicating satisfaction from caring supports the suggestion that the positive aspects of caring have not been given due attention in much of the previous research on the effects of caring.

#### 4.2.1.4 What are the factors associated with carers' perceived competence in the caring role?

Female carers in both groups often mentioned surprise at their ability to cope with the demands of caring – especially at a practical level – and linked this to an increased sense of competence. The nature of the dementing process means carers will have to find ways to manage new problems relating to the cognitive and functional decline of their dependant. As they adapt to or 'master' one problem another is likely to appear, making the maintenance of perceived competence a dynamic process and linking it with a sense of efficacy in adapting to and managing changing situations. This was nicely demonstrated by TE, a male spouse carer, who linked his competence to his ability to "stay in charge", which in turn was linked to his ability to adapt to his wife's ever-changing needs.

#### 4.2.2 Comparisons with the empirical research on caring

Levels of anxiety and depression: Other clinical samples have tended to report rates of depression starting at around 30%, and in this study 27% of participants reached clinical levels of depression. Anxiety rates in the study were higher than expected at 36%, but the small sample size must be borne in mind. However, the results from postal survey responses to the CADI are interesting in this context, suggesting an inability to relax was a major difficulty for carers. These findings lend some support to the suggestion that focusing on the instrumental aspects of care will not provide a sufficient account of the stresses of caring, which may involve a high level of 'invisible' stressors.

Physical health status: Zanetti et al (1998) found perceived health status was a strong independent predictor of depressive symptoms in carers. Three female carers in the present study disclosed serious health problems of their own in the course of the interviews, and expressed concerns about the effects of caring on their health. In all cases their conditions pre-dated becoming a carer.

Grief reactions: The theme of loss and change emerged from the initial IPA thematic analysis of data, but was subsumed within the 'emotional impact of care' in the subsequent analysis. There were many comments relating to a sense of loss of aspects of the person with dementia, and oblique references to the loss of mutuality that was highlighted in the literature review (e.g. Garner, 1997).

Patient related variables: There were no behavioural difficulties that all carers mentioning regarded as problems in their own right. Thus incontinence was seen as very stressful or beyond the limits of two carers, but to another it was her husband's denial of the problem that caused the greatest stress. In general, the stresses referred

to in relation to apparent behavioural problems were more concerned with the emotional implications of the behaviour to the carers, such as MS's husband's tendency to confuse her with his sister. Other problem behaviours arising from memory impairment (e.g. repeated phone calls, or forgetting how to do things) were seen as stressful.

**Models of care:** The empirical literature highlighted possible gender differences in the way carers conceptualise their role, such that men tend to see it as an extension of their work skills and women see it as a continuation of previous nurturing roles. In the present study, only women carers explicitly discussed these role issues, but did so in terms of either "nurse-patient" or "mother-child" models.

**Relationship type:** Unfortunately there were no son carers in the adult child group. None of the daughter carers mentioned their husbands' active involvement in 'hands on' care of their dependant, in line with Horowitz's (1985) finding that son carers expected active involvement by their wives, but daughter carers expected their husbands to remain 'neutral' and not object to their care-giving activities.

**Sense of self and values:** The findings of the present study support Lawton et al's (1989) suggestion that caring can be appraised in positive and negative ways, and that it is necessary to consider both when looking at the impact of caring. There was evidence that people were prepared to make considerable and conscious sacrifices in order to fulfill their caring role, which indicates that these were considered worthwhile.

### 4.2.3 The theoretical perspective

The findings of the present study support aspects of both the Stress Process Model (Pearlin et al, 1990) and Bowers' (1987) model. The Stress Process Model identifies three main components of primary subjective stressors: role overload, role captivity and loss of relationship with the dependant. There was evidence of all these in the interview data. Similarly, stress proliferation, in which the stresses of caring spill over and effect other aspects of the carer's life, and stress containment, in which available resources are used to help contain and manage the stress were in evidence. Carers in general seemed to cope better while they were able to use preferred methods of stress containment, which appeared to involve having time to pursue their own interests or hobbies in many cases, and it was when these opportunities became more difficult to arrange or impossible that stress proliferation was apparent.

Of particular interest theoretically is Bowers' model. She proposed re-formulating caring to focus on the purposes of care, rather than the instrumental aspects, and this may shed some light on the positive aspects of caring in particular. For example, if the purpose of care in a given situation is protective, aiming to maintain a sense of self esteem and independence for the care recipient, achieving this aim may be more rewarding to the care-giver than a good 'instrumental' outcome. The results from both the interviews and the CASI indicate that providing effective protective care may underlie some of the most satisfying aspects of caring for a family member with dementia. Thus the item rated most rewarding on the CASI was 'Maintaining the dignity of the person I care for is important to me', with 87.5% of survey respondents indicating it gave them satisfaction.

In terms of accounting for the results obtained it would seem that both the Stress Process Model and Bowers' model provide useful ways to conceptualise the stresses or difficulties of caring. Bowers' model also provides a framework for understanding some of the rewards or satisfactions of caring, which are not really accounted for in Pearlin et al's model.

#### 4.2.4 Clinical implications for local services

There are a number of implications for local clinical services arising out of the finding of the present project. The fact that some of the carers had been unaware that their relative had dementia or what the implications of taking on care would be for them supports the usefulness of having an early diagnosis and follow-up service, offering education, advice and support tailored to the individual's needs. The local service has been working with local General Practitioners towards earlier identification of dementia in the population, with referral on to appropriate specialist services and easily available information on dementia. A rolling programme of carers' educational groups are planned to start in Autumn 1999. Having a greater understanding of the changes they witness in their relative may help reduce the perception that carers are being 'played up'. It could be argued that giving people more information about the problems that may lie ahead and the likely course of dementia may increase carers' anxieties, but the study by Graham et al (1997) indicated that although more knowledgeable carers had higher levels of anxiety, they had lower levels of depression and felt more competent.

A useful suggestion was made for easier access to a range of named 'specialist' practitioners (for example, opticians, chiropodists, dentists) who are experienced and

willing to see patients who are in the more advanced stages of dementia. This task could be taken on by the voluntary or statutory sector.

#### **4.3 Conclusions and implicatons for further research**

In order to obtain a clearer idea of the process of caring in dementia, there is a pressing need for some longer term prospective studies, to follow the natural progression of the condition and its impact on both the care-giver and care-recipient. Ideally this would include both quantitative data from large samples and qualitative data. The quantitative data should include male and female carers and compare different types of family relationships, to clarify the role of gender versus relationship. In order to utilise the strengths of a qualitative approach an in-depth study could be made with a small number of dyads of carer and care recipient, in which both would be interviewed regularly over a period of years, through the duration of care at home, and, if appropriate, in residential settings. This would shed more light on the ways in which people make sense of their experiences, and adapt to the ever changing problems that dementia presents, and would address current imbalances in terms of positive and negative aspects of care and the perspectives of both care-giver and care recipient.

Caring for a family member with dementia is qualitatively different to caring for a family member with a physical disability. As Garner (1997) pointed out, even in the early stages of dementia important aspects of the person can change, leading to a sense of loss and changes in the relationship between care giver and care recipient. The project's results lend weight to the argument that focusing on instrumental aspects of care is unhelpful. The main stresses for spouse/partners related to emotional and relationship issues, with the effect of behavioural problems being



mediated by the meanings of these behaviours for the carers. Quantitative data supported the contention that the emotional consequences of caring were seen as especially stressful, along with practical restrictions such as lack of private time.

Similarly, the most satisfying aspects of caring related to emotional and relationship issues. In particular it is suggested that fulfilling one's idea of what is 'right and proper' within a specific relationship was an underlying construct for both groups of participants. Failure to achieve the desired purposes of care may lead to lower self esteem and reduced perceived competence, but success may reinforce the sense that sacrifices made and stress experienced are worthwhile. There is scope for much more research incorporating both the negative and positive aspects of care, and Bowers' model would seem to provide one framework within which the satisfying elements of caring can be conceptualised.

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## **List of appendices**

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Our ref:

Your ref:

**CONFIDENTIAL**

Dear

I am writing to ask if you could take the time to complete the attached brief questionnaire about the service you received from the One Stop Project. The project was set up in April 1996 to provide a more co-ordinated service to people thought to be suffering from dementia and their carers.

In planning for future developments and improvements to the project we need to evaluate how useful different aspects of its work are now. We would be glad to receive your comments and views on your contact with the project. Confidentiality is guaranteed; the questionnaires are anonymous and project workers will not see any of the responses.

Apart from the attached questionnaire we are also hoping to gain additional detailed information from you on the stresses and rewards of caring. To this end I have enclosed a separate envelope containing two more questionnaires. We would be very grateful if you could spare the time to fill them in, but if you are unable or unwilling to do so, please return them in the envelope provided.

We would also like to meet a small number of carers individually to gain a fuller understanding of your experience of local services, and to give you a chance to raise issues that may have been very important to you in your role as a carer, but which do not appear on our questionnaire/s. If you would be willing to participate in this part of the research, please complete the attached slip and return it with your questionnaire/s.

Thank you for your help.

Yours sincerely,

**Meg Rolleston**  
**Chartered Clinical Psychologist to Older People**

Enc.

In addition to the Dementia Project Evaluation, I am involved in a further research project looking at the experiences of family members caring for someone with dementia. This can be a difficult and stressful role to take on, but some people also find aspects of the role can be rewarding or satisfying. I am currently seeking family carers (either spouses or adult children of someone with dementia) who would be willing to be interviewed about their experiences of caring, and to complete a brief questionnaire. It is estimated that the total time involved would be approximately one and half hours per person. All information would be strictly confidential. Interviews could take place in an NHS setting or in your own home - whichever you prefer.

The information gained will be used to try and improve services for family carers in the Trust area, based on carer's views of what helps and hinders the caring process.

If you would be willing to be contacted with a view to arranging a convenient time to meet, please complete the consent slip below and return in the envelope provided.

Thank you for your help,

**Meg Rolleston**  
**Chartered Clinical Psychologist**

NAME: .....

ADDRESS: .....

.....

TEL No: .....(if you are willing to be contacted by phone)

Please tick whether you are the:

Husband ☐

Wife ☐

Son ☐

Daughter ☐

of someone with dementia



Our ref:

Your ref:

**CONFIDENTIAL**

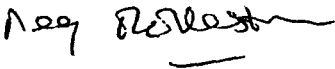
**Re: Research on Family Care-giving and Dementia**

You kindly agreed to participate in my research on family care-giving and dementia. I am sorry for the delay in contacting you to arrange the brief interview. I am planning to conduct these between January and March 1999, and am writing to let you know that I will be in contact by phone shortly to arrange a convenient time to meet.

If you have changed your mind or are no longer able to participate, please return the slip below to ensure you are not contacted unnecessarily.

With many thanks for your help.

Yours sincerely,



**Meg Rolleston**  
**Chartered Clinical Psychologist**

NAME: .....

I am no longer able to participate in the research on family care-giving and dementia.  
Please do not re-contact me.

I am involved in a research project looking at the experiences of family members caring for someone with dementia. This can be a difficult and stressful role to take on, but some people also find aspects of the role can be rewarding or satisfying. I am currently seeking family carers (either spouses or partners of someone with dementia) who would be willing to be interviewed about their experiences of caring, and to complete a brief questionnaire. It is estimated that the total time involved would be approximately one and half hours per person. All information would be strictly confidential. Interviews could take place in an NHS setting or in your own home - whichever you prefer.

The information gained will be used to try and improve services for family carers in the \_\_\_\_\_ area, based on carer's views of what helps and hinders the caring process.

If you would be willing to be contacted with a view to arranging a convenient time to meet, please complete the consent slip below and return in the envelope provided.

Thank you for your help

**Meg Rolleston**  
**Chartered Clinical Psychologist**

-----

NAME: .....

ADDRESS: .....

.....

TEL NO. .... (if you are willing to be contacted by phone)

Please tick whether you are the:

- Husband ☐
- Wife ☐
- Partner ☐

of someone with dementia

**BEST COPY**

**AVAILABLE**

TEXT IN ORIGINAL IS  
CLOSE TO THE EDGE OF  
THE PAGE

**BEST COPY**

**AVAILABLE**

Some text bound close to  
the spine.

**BEST COPY**

**AVAILABLE**

Variable print quality

Below are some statements which carers have made about the difficulties they face. Please read each statement and show if it applies to you by ringing the appropriate number in Column A. For each statement which sometimes or always applies to you, please show how stressful you find it by ringing the appropriate number in Column B.

## Column A

## Column B

## This statement

## I find this aspect of caring

CARING CAN BE DIFFICULT BECAUSE	Column A			Column B		
	Always applies to me	Sometimes applies to me	Never applies to me	Very stressful	Moderately stressful	Not stressful
1) I don't have enough private time for myself	3	2	1	3	2	1
2) I can feel helpless/not in control of the situation	3	2	1	3	2	1
3) I can't devote enough time to other family members	3	2	1	3	2	1
4) It causes financial difficulties	3	2	1	3	2	1
5) The person I care for can play me up	3	2	1	3	2	1
6) The person I care for is immobile/has problems getting about	3	2	1	3	2	1
7) Professional workers don't seem to appreciate the problems carers face	3	2	1	3	2	1
8) It restricts my social life/outside interests	3	2	1	3	2	1
9) It can put a strain on family relationships	3	2	1	3	2	1
10) It is physically tiring	3	2	1	3	2	1
11) The person I care for can demand too much of me	3	2	1	3	2	1
12) I no longer have a meaningful relationship with the person I care for	3	2	1	3	2	1
13) The person I care for needs a lot of help with personal care	3	2	1	3	2	1

	Column A			Column B		
	This statement			I find this aspect of caring		
CARING CAN BE DIFFICULT BECAUSE	Always applies to me	Sometimes applies to me	Never applies to me	Very stressful	Moderately stressful	Not stressful
29) I can't relax because of worry about caring	3	2	1	3	2	1
30) I feel guilty about the situation	3	2	1	3	2	1

	Column A			Column B		
	This statement			I find this aspect of caring		
CARING CAN BE DIFFICULT BECAUSE	Always applies to me	Sometimes applies to me	Never applies to me	Very stressful	Moderately stressful	Not stressful
This list may not have contained all the difficulties which you face. If you feel that any were missing could you please add them below. For each statement you add please also indicate their frequency and how stressful you find them:						
	3	2	1	3	2	1
	3	2	1	3	2	1
	3	2	1	3	2	1

THANK YOU VERY MUCH FOR YOUR HELP

\* CADI was first published by M Nolan and G Grant in *Regular Respite: An Evaluation of a Hospital Rota Bed Scheme for Elderly People*. Age Concern Institute of Gerontology, Research Monograph Series, July 1992, ISBN 0 86242 115 2

## THE CARER'S ASSESSMENT OF SATISFACTIONS INDEX (C A S I)\*

This questionnaire is concerned with those aspects of caring which you may find provide you with some satisfaction. The following 30 statements have all been made by carers and we would be interested to know if they apply to you. However, please do not worry if very few of the statements apply to you, it is still important that we know this. As each carers' situation is unique, people respond in different ways.

Please read each item and show how it applies to you by circling the number which reflects your response.

Caring can be satisfying because:	This applies to me and provides me with:			
	A great deal of satisfaction	Quite a lot of satisfaction	No real satisfaction	This does not apply to me
Caring has allowed me to develop new skills and abilities	4	3	2	1
The person I care for is appreciative of what I do	4	3	2	1
Caring has brought me closer to the person I care for	4	3	2	1
It's good to see small improvements in their condition	4	3	2	1
I am able to help the person I care for reach their full potential	4	3	2	1
I am able to repay their past acts of kindness	4	3	2	1
Caring provides a challenge	4	3	2	1
Despite all their problems the person I care for does not grumble or moan	4	3	2	1



Caring can be satisfying because:	This applies to me and provides me with:			
	A great deal of satisfaction	Quite a lot of satisfaction	No real satisfaction	This does not apply to me
I feel that if the situation were reversed, the person I care for would do the same for me	4	3	2	1
I am able to ensure that the person I care for has their needs tended to	4	3	2	1
Caring has given me the chance to widen my interests and contacts	4	3	2	1
Maintaining the dignity of the person I care for is important to me	4	3	2	1
I am able to test myself and overcome difficulties	4	3	2	1
Caring is one way of showing my faith	4	3	2	1
Caring has provided a purpose in my life that I did not have before	4	3	2	1
At the end of the day I know I will have done the best I could	4	3	2	1
Caring is one way of expressing my love for the person I care for	4	3	2	1
Caring makes me feel needed and wanted	4	3	2	1

THANK YOU VERY MUCH FOR YOUR HELP

Name:

Date:

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be able to help you more.

This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

*Tick only one box in each section*

## I feel tense or 'wound up':

- Most of the time .....  
A lot of the time .....  
Time to time, Occasionally .....  
Not at all .....


## I feel as if I am slowed down:

- Nearly all the time .....  
Very often .....  
Sometimes .....  
Not at all .....


## I still enjoy the things I used to enjoy:

- Definitely as much .....  
Not quite so much .....  
Only a little .....  
Hardly at all .....


## I get a sort of frightened feeling like 'butterflies' in the stomach:

- Not at all .....  
Occasionally .....  
Quite often .....  
Very often .....


## I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly .....  
Yes, but not too badly .....  
A little, but it doesn't worry me .....  
Not at all .....


## I have lost interest in my appearance:

- Definitely .....  
I don't take so much care as I should.....  
I may not take quite as much care .....  
I take just as much care as ever .....


## I can laugh and see the funny side of things:

- As much as I always could .....  
Not quite so much now .....  
Definitely not so much now .....  
Not at all .....


## I feel restless as if I have to be on the move:

- Very much indeed .....  
Quite a lot .....  
Not very much .....  
Not at all .....


## Worrying thoughts go through my mind:

- A great deal of the time .....  
A lot of the time .....  
From time to time but not too often...  
Only occasionally .....


## I look forward with enjoyment to things:

- As much as ever I did .....  
Rather less than I used to .....  
Definitely less than I used to .....  
Hardly at all .....


## I feel cheerful:

- Not at all .....  
Not often .....  
Sometimes .....  
Most of the time .....


## I get sudden feelings of panic:

- Very often indeed .....  
Quite often .....  
Not very often .....  
Not at all .....


## I can sit at ease and feel relaxed:

- Definitely .....  
Usually .....  
Not often .....  
Not at all .....


## I can enjoy a good book or radio or TV programme:

- Often .....  
Sometimes .....  
Not often .....  
Very seldom .....


Do not write below this line

**LOCAL RESEARCH ETHICS COMMITTEE**  
**PLEASE NOTE THIS FORM MUST BE TYPEWRITTEN**

Appendix 8

**1. TITLE OF PROJECT**

Family caregiving and dementia: difficulties and rewards of caring and an exploration of mediating factors in taking on and continuing the caregiver role.

**2. STARTING DATE**

July 1998

**INVESTIGATOR(S)**

**NAME:** Margaret Rolleston

**QUALIFICATION:** BSc., Dip.Clin. Psychol.

**WORK ADDRESS:**

**WILL OTHER STAFF/WORKERS BE INVOLVED IN THE RESEARCH PROJECT?**

**Nursing Staff (give particulars of involvement):** Some CPNs in Borough may be involved in identifying potential participants.

**Laboratory Staff:** None

**Any Other Staff:** None  
(List other works from any statutory, non-statutory or voluntary groups.)

**WHERE WILL THE RESEARCH BE DONE?:**

**In the participant's home?:** possibly

**In Doctor's surgery?:** no

**In hospital ward outpatients?:** no

**Other, please specify:** Participants will be able to choose whether they are seen in their own homes or on Trust premises (eg. Psychology Dept)

**If, while inpatient, will this research involve an extended stay in hospital? If so, how long?:**

**If in outpatients, please give details:**

**BACKGROUND OF THE STUDY:** This study will be written up as the Research<sup>h</sup>

Dissertation for a Post Qualification Doctorate degree in Clinical Psychology.

There has been a substantial amount of research interest in the factors contributing to carer burden in family members caring for someone with dementia, but comparatively little research on the positive factors that may motivate people to take on and continue this role. Although perceived competence is known to be an important factor in determining levels of job satisfaction in paid employment, it is not known to what extent this may also play a role in mediating the stresses and rewards of caring for someone with dementia.

### AIMS OF THE STUDY:

(Please include anticipated clinical use of outcomes, the potential benefit to the participant and the potential benefit to medical science.)

To clarify the factors that motivate family caregivers to take on and continue the caregiving role;  
To explore the main difficulties and rewards of caring for a family member with dementia;  
To explore the factors that positively or negatively influence the subjective experience of caring for a family member with dementia, including the role of perceived competence as a potential mediating factor.

It is in the interests of both family caregivers, care recipients and funding services to this client group to clarify those issues contributing to carer stress and coping, in order to target services more effectively. The results of this study will be fed back into Mental Health Services for Older People within

NHS Trust, which is where the investigator and Research Supervisor both work. Participants may be able to benefit from any service initiatives that result.

### DESIGN OF THE STUDY:

The study will employ both a cross-sectional postal survey and semi-structured interviews.

Postal Survey: The researcher has already undertaken the first part of a two part postal survey of carers who received a service from the Department of Health funded Dementia Care Project in the Trust. The Project ran from April 1996 to March 1998, and the researcher had responsibility for devising and conducting a carer satisfaction survey. The mailing containing the carer satisfaction survey also contained standardised questionnaires on the difficulties and rewards of caring, which participants were asked if they would be willing to complete and return.

It is proposed to use data from both collection points as part of the present project.

Semi-structured interview: It is proposed to use a semi-structure interview with a small sample of carers - half spouse/partners and half sons/daughters of a care recipient with dementia.

Recruitment: This will be by two means.

1. Dementia Care Project evaluation. The investigator will be mailing the second evaluation to carers who received a service from the Project. It is proposed to include in the mailing a request for volunteers for interview. An outline of the research will be given and people who are willing to participate will be asked to complete a separate form, consenting to be contacted in the first instance.

2. The CPNs in Borough run a regular group for carers of people with dementia. It is proposed to ask the CPNs for the names of potential participants for the study, who would need to satisfy the existing exclusion criteria for carers in the evaluation study.



**PARTICIPANTS:**

Please state:

- a) The number of participants to be studied: 2 groups of 6-8, making 12-16 people in all
- b) The number of healthy volunteers to be studied: 12-16.
- c) Age range: Adults
- d) Method of recruitment: postal request for volunteers from enhanced services.
- e) Exclusions: People for whom it may be distressing or otherwise inappropriate
- f) Details of any payments or other inducements to be made to to contact, identified by CPNs.
  - the participants: none
  - i) Expenses: none
  - ii) Financial or other rewards: none

**DETAILS OF PROCEDURES, IF APPROPRIATE:**

- a) **DRUG NAME:** N/A

**FORMULATION:**

**DOSE/FREQUENCY:**

**ROUTE OF ADMINISTRATION:**

**LEGAL STATUS:**

(CTC, CTX,  
PRODUCT LICENCE):

What adverse effects are expected with these drugs?:

Are there any possible serious risks or dangers with their use? (Append details if insufficient space):

- b) **ISOTOPES:** N/A

Details of any isotopes to be used including dose, frequency and route:

- i) Has advice of the Radiation Protection Officer been sought?:
- ii) Has the applicant a DHSS Licence for this purpose?:
- iii) Specify a routine investigation or equivalent radiation exposure:

- c) **OTHER ADDITIONAL INVESTIGATIONS, SUBSTANCES OR AGENTS REQUIRED FOR RESEARCH:** NONE

(Including cardiac catheterisation, ultrasound, radiography, ECG, EEG, etc) Please specify:

- d) **QUESTIONNAIRES:**

(Please attach a copy of any questionnaire to be used)

Are the questionnaires to be filled in by the participant or administered by someone else?:

Administered

If so, by whom, and by what method (e.g. postal): by the researcher during the course of the interview

What published evidence is there as validation of questionnaire design?:

Zigmond, A.S. and Snaith, R.P. (1983) The Hospital Anxiety and Depression Scale. Acta Psychiatrica Scandinavica, 67,361-370.

**PHARMACEUTICAL COMPANY INVOLVED**  
**FUNDING ARRANGEMENTS:**

Does the project involve participation or sponsorship by a pharmaceutical company?:

YES/NO

If so, which company?

If so, has the company signified its acceptance of the ABPI Guidelines?:

YES/NO

If so, what kind of financial support will be provided by the pharmaceutical company (if any)?:

Please describe the level of support (per patient if appropriate):

Will you or other investigators receive any material benefits from the study (equipment, research salaries or other gains)?:

**WHAT ASPECT OF THE PROCEDURES DESCRIBED ARE NOT PART OF ROUTINE CLINICAL CARE?:**

N/A

**THE HEALTH & COMFORT OF THE PARTICIPANTS:**

Will there be any risk of damage to the health of the participants, or any pain, discomfort, distress or inconvenience?

If so, please give an assessment of the seriousness of any possible damage to health, and of any pain, discomfort, etc.,

and the degree of risk: Each participant will be interviewed about the experience of caring for a relative with dementia. They will be asked to complete a brief questionnaire. Total estimated contact time is 1½ hours. The interview may touch on distressing issues, but participants will be free to avoid answering any questions they may find too distressing.

**CONSENT:**

Will participants be asked for their informed consent?: Yes

Will this be given an oral, a written or no explanation of the research?:

Written and oral

If a written explanation is to be given, a copy must be attached.

Please justify oral or no explanation:

Is the Local Research Ethics Committee's consent form to be used?:

No

If not, please justify and attach a copy of the substitute form: The existing form does not seem appropriate to my study, which is with carers rather than patients. An alternative form is attached.

15. **INFORMATION TO THE GP:**

Will the General Practitioner be informed?: No

If so, how?:

If not, justify: The data collection will be confidential. All participants will be seen as carers rather than patients in their own rights. All will have received an enhanced service (The Dementia Project or s' Group) and will have access to these services or CPN support if necessary.

16. **COSTS IF APPROPRIATE:**

a) Have any arrangements been made to defray costs of the research to the Trust?: Interviews will take place in the researcher's own time. There are no anticipated cost implications for NHS Trust.

b) What are the implications of this study to the following grades of staff?: None

- Junior Medical
- Nursing
- Clerical
- Technical/PAMS
- Other

c) What are the implications for other patients not affected by the study, i.e. will it affect waiting lists, etc?: None

17. **WHAT ARE THE ETHICAL ISSUES WHICH APPEAR TO THE PARTICIPANTS TO ARISE FROM THIS APPLICATION?:**

Please set them out and add any comments considered likely to assist the Committee:

The main ethical issue appears to be the risk of identifying a high level of stress/depression in a carer, without built in recourse to their health care team. In such a situation I would propose to discuss the need for appropriate help with the participant, and would encourage them to seek this themselves or allow me to pass on the information to their health care team (eg. GP or CPN). All participants would have an enhanced chance of receiving appropriate psychological intervention if they wished, and would continue to have access to ongoing support from a CPN.

18.

**COMPLETION:**

The Committee expects to receive the results of this research project.

It is intended to submit the Dissertation for examination in May 1999. The Committee would receive a copy of the final, passed Dissertation.

19.

**SIGNATURE OF LOCAL INVESTIGATOR:**M. Rolleston**NAME:** MARGARET ROLLESTON**DATE:** 1st June 1998.

20.

I have read this application. I am aware of its contents and also aware of the impact on service and I support it.

Dear Ms Rolleston

RE: FAMILY CAREGIVING AND DEMENTIA: DIFFICULTIES AND REWARDS OF CARING AND AN EXPLORATION OF MEDIATING FACTORS IN TAKING ON AND CONTINUING THE CAREGIVER ROLE

**SIGNATURE:** \_\_\_\_\_  
**HEAD OF DEPARTMENT/CLINICAL DIRECTOR**

**NAME:** \_\_\_\_\_**DATE:** 1.6.98

**SIGNATURE:** \_\_\_\_\_  
**CHIEF EXECUTIVE OF TRUST**

**NAME:** \_\_\_\_\_**DATE:** \_\_\_\_\_



## LOCAL RESEARCH ETHICS COMMITTEE

### INFORMATION SHEET

1 July 1998

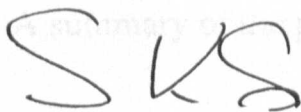
Ms Margaret Rolleston  
Chartered Clinical Psychologist

Dear Ms Rolleston

**RE: FAMILY CAREGIVING AND DEMENTIA: DIFFICULTIES AND  
REWARDS OF CARING AND AN EXPLORATION OF MEDIATING  
FACTORS IN TAKING ON AND CONTINUING THE CAREGIVER ROLE**

I am writing to advise you that at the meeting of the Local Research Ethics Committee held on Friday, 26 June 1998 the above protocol was discussed in great detail by the Committee and was given full approval.

Yours sincerely



Secretary

LREC

## **INFORMATION SHEET**

**Family caregiving and dementia: difficulties and rewards of caring and an exploration of mediating factors in taking on and continuing the caregiving role.**

This research project is looking at the stresses and rewards of caring for a family member with dementia. Information will come from two sources: questionnaires and interviews.

There will be three questionnaires, two of which will be sent to carers who have had contact with the S Trust dementia service. One brief questionnaire will be completed as part of the interview, which people can volunteer to participate in. The total time commitment will be about one to one and a half hours. The interviews will focus on the carer's subjective experience of looking after a family member with dementia. Interviews may be terminated at any time if the participant wishes.

All information gained as part of the research will remain completely confidential.

A summary of the project can be sent to participants who are interested.

**CONSENT FORM**

I ..... (full name)  
of ..... (address)

.....  
hereby fully and freely consent to participation in a research project entitled:  
.....  
.....  
.....

I understand and acknowledge that the project is designed to promote knowledge of what helps and hinders caring for a family member with dementia.

I have been given an information sheet, which I have read and understand, and which I can keep for future reference.

I understand that I may withdraw my consent at any stage in the research.

Signed: .....

Name (in capitals): .....

**DECLARATION BY THE RESEARCHER**

I confirm that I have explained the nature of the interview to the person named above, and that his/her consent has been given freely and voluntary.

Signed: .....

Status: .....

Date: .....

### **Research diary**

**6/7/98** Received ethics approval today, so can proceed with the next mailing of the postal survey.

**6/8/98** All the letters went out this week. The response from people willing to be interviewed last year was good (for the SSRP), so I am hopeful of getting a good response now too.

**23/9/98** The response was okay, but I have had to exclude a couple (not related to care recipient or relative is already in care). Have also heard that death or illness of carers/care recipient means some more losses. Have spoken to Jane about using the carers' group as another potential source of participants, and she thought this would be fine – especially as they are also involved in a clinical service, like the other participants. Will write to carers' group facilitators with details, since they already know about the project in outline.

**12/10/98** Have sent letter to people in the carers' group. Facilitator is going to explain project briefly and ask anyone interested to take a letter and return to me with their details. Must shape up the questions for the interview. I have lost the ones I drafted in the summer, so will have to start from scratch again.

**6/11/98** Spent the morning working on the questions, then found the ones I drew up earlier. Almost identical questions and wording. Will send them to Jane for comments when they have been typed up. I have tried hard to keep the number of questions down because I don't want to have too much data to use and I know qualitative analysis is very time consuming. Have estimated an hour to an hour and a half per interview, including going through the HAD and consent forms etc.

**26/11/98** Jane suggested a few word changes to make the questions more open. I was hoping to get started on the interviews before Christmas, but am now taking time off to move house instead. Hoping to start in January instead. The first couple of interviews will be pilots for the rest.

**11/1/99** I have contacted some of the participants to agree interview dates, but quite a lot have been unavailable when I have rung. Secretary has kindly agreed to contact them and I have given a long list of my availability over the next couple of months.

**22/1/99** First interview. GP, a wife carer. I was worried about her stress levels and stayed on for a while to discuss pacing and additional sources of support. The interview was much shorter than I had expected.

**25/1/99** Pilot interview of daughter carer. Rather hectic environment since she also cares for her young grand-daughter during the day, so television was on to keep her occupied while we talked. EB didn't find any aspects of caring rewarding, but talked about her frustration. Again, the interview was quite short. Being unfamiliar with qualitative methods I am a bit uncertain how much it is okay to deviate from the questions.

29/1/99 I think I will change the order of questions around in the interview to allow people to talk about their stresses and frustrations before I ask about rewarding or satisfying aspects of care. Maybe it will be easier for people to relate to the question if they have 'off-loaded' their stresses first?

17/3/99 The whole process of collecting data has been affected by factors outside work. Because I am going to the hospital every evening I am having really long days and my mind is on other things. I am moving house again next week so that I can take care of my father when he gets out of hospital and am really trying to get the interviews done before Easter: a) because I am on annual leave, so can fit them in to suit the interviewees more and b) because I don't know how caring at home is going to fit in with getting my work done, so I want to get as much done now as possible. I have seen six people so far, and have got appointments for another four next week.

13/5/99 Another long break due to my circumstances. Am now back at work part-time but it is proving difficult to fit everything in. Final interview today, with MS. She was assessed by a care manager a couple of months ago and her husband referred to a day centre, since when they have heard nothing. She is very stressed, so I stayed on for quite a while and have arranged to see her again in a couple of weeks, just until the additional input is sorted out. Phoned social services to chase up the referral.

5/7/99 I have found it very hard to get back to my research, but have now got a couple of weeks of leave in which to work on the write-up. Hoping to analyse the data in the second week but need to get the introduction done first.

13/7/99 Started the thematic analysis. Not too sure about the 'interpretative' stage of the process and have stuck to descriptions of the data which are as 'objective' as possible. I am finding a conflict between the qualitative methodology I have selected (for good reasons) and my own background in quantitative methods. Have been looking in to issues of reliability and validity more and have asked LF to be second rater. It is too late to send the transcripts back to the participants now – it is four or five months since some were interviewed - but I am not convinced by the idea of respondent validity in the context of dementia anyway. Since dementia is a progressive condition carers' perceptions of how they are doing can change quite dramatically in a short space of time, depending on the health of the person they are caring for. I know a couple of the care recipients from the sample have been admitted to hospital since I saw them. I summarised the main points from the interviews at the end of most, so I am pretty confident I recorded the gist of what the participants said at the time.

23/7/99 Having identified the themes from the group analyses I cannot answer the research questions systematically. Have looked at the Smith papers again and decided the only way to do so is to go through the procedure again taking only those parts of the interview that relate directly to a particular research question. Laborious.

23/8/99 I have got another block of time off to finish the first draft.

3/9/99 Feedback from Jane re the data management (as described on 23/7). She suggests I should put both versions in the results and be clearer about the actual procedures followed. There won't be room for all the descriptors, so the ones relating

to the initial thematic analysis will have to go in to appendices. Since they duplicate much of what it is the main body of the text I don't think this will be problematic. We have agreed that I should include the interview transcripts in the appendices or as a separate bound attachment, even though the Regulations say you don't need to put raw data in. I feel happier about this because I think the richness of the individual's data have been lost in the reductionist methodology. Would be interested in doing a much more in-depth study of just one or two carer-dependant dyads following them over an extended period of time.

13/9/99 Received the second rater information back and have started going through this looking at agreement. In nearly all cases we identified the same underlying issues, but have labelled things differently at times.

17/9/99 Having calculated the Kappa co-efficients, there were a couple of instances where I decided to combine confusing categories for the sake of clarity and higher agreement. I have also finished summarising the results of the CADI and CASI, which are interesting, and tie in quite well with my findings. Have become more enthused by the research again now that I am pulling it together.

24/9/99 Finished the writing and formatting. I think my unfamiliarity with the methodology has been unhelpful, but I have learned a lot in the process. I still feel caught somewhere between the qualitative and quantitative paradigms, and would want to give a lot of thought to any further qualitative research to ensure I got the most out of it.

**Inter-rater reliability**  
**Tables showing the themes identified by each rater**

The table below shows the themes identified by each rater for the interview transcript of WG. The left hand columns show the themes and sub themes identified by the researcher, and the right hand column shows the themes identified by the second rater in relation to the same pieces of text.

1 <sup>st</sup> rater – main themes	1 <sup>st</sup> rater – sub themes	2 <sup>nd</sup> rater
Care recipient	Onset of dementia Behaviour/dementia Physical health Change and loss Self concept/emotional care provision Sisters Other family responsibilities	Taking on care  Changes in person Father's emotional well being/offering emot. Support Family network/family support
Family		
Services/getting help		
Self	Impact on her – emotional Impact on her – work/time Practical care Managing father's behaviour Competence and coping  Looking ahead  Rewards and motivators  Values and beliefs  Positive self evaluation Limits	Difficulty obtaining help Emotional impact Impact on her time Practical aspects Learning how to cope Competence and learning how to cope May be easier in future Letting go Quality of relationship Satisfaction and gratitude Religious beliefs Social network Self perception Intensive weekly routine

The table below shows the themes identified by each rater for the interview transcript of GP. The left hand columns show the themes and sub-themes identified by the researcher and the right hand column shows the themes identified by the second rater in relation to the same pieces of text.

1 <sup>st</sup> rater – main themes	1 <sup>st</sup> rater – sub themes	2 <sup>nd</sup> rater
Care recipient	Onset of dementia	Role transition Changes in his health Behavioural changes Loss and sadness
Self	Dementia/behaviour Loss Personality Impact – emotional Impact – practical  Physical care Physical health Coping  Responsibility and competence  Satisfaction	Impact on self – loss Impact – exhaustion Impact – domestic Physical aspects of caring Hoping for stability Adaptation of own responses Learning how to respond Practical aspects of caring Unexpected competencies Competence comes from coping
Family		Family involvement and support
Services		External practical support

The table below shows the themes identified by each rater for the interview transcript of NJ. The left hand columns show the themes and sub-themes identified by the researcher and the right hand columns show the themes identified by the second rater in relation to the same pieces of text.

1 <sup>st</sup> rater – main themes	1 <sup>st</sup> rater – sub themes	2 <sup>nd</sup> rater
Care recipient	Deterioration/loss Dementia/behaviour	Recognition of dementia Increase in difficulties Behaviour
Self	Personality  No choice taking it on Practical changes and restrictions  Normal/abnormal Coping  Limits  Positive perceptions Competence-coping  Benefits	Personality Quality of relationship Lack of choice Practical impact Restrictions and loss of independence Social comparisons Cognitive coping Learning to cope with the demands Own limits Recognition of limits Reached the limit Positive impact Changing self concept Discovery of competence Social benefits and support Social contacts Material benefits
Model of care		

The table below shows the themes identified by each rater for the interview transcript of MS. The left hand columns show the themes and sub-themes identified by the researcher and the right hand cloumns show the themes identified by the second rater in relation to the same pieces of text.

1 <sup>st</sup> rater – main themes	1 <sup>st</sup> rater – sub themes	2 <sup>nd</sup> rater
Care recipient	Onset of dementia Physical health Behaviour/dementia Others help	Behaviour Others – lack of awareness Emotional consequences Guilt
Self	Emotional impact  Coping  Managing care Competence Satisfaction/motivation Limits/future	Practical coping Trying to find ways of coping Physical aspects
Relationship Services Family		Goal of keeping him at home Quality of relationship



**Agreement co-efficients with second rater  
in relation to excerpts from the text  
sorted in to given themes  
for each research question**

Kappa co-efficients were calculated for each research question in the following way. The researcher took excerpts from the text that demonstrated the themes identified for each research question – the number of excerpts varied from 10 to 30 – and sent them to the second rater, having separated the excerpts in to those relating to spouse/partners and adult child carers. The excerpts were randomly presented. For each group the themes into which they should be sorted were given, and the second rater then completed this task, noting on the back of each excerpt the theme to which she thought it related. The sorted excerpts were returned to the researcher, who calculated percentage agreements and Kappa co-efficients for each question. The calculation are shown below.

**What factors play a part in the decision to take on caring for a family member with dementia?**

Identified themes	Agreement
<u>Spouse/partners</u>	
Care recipient's need	4/4
Perceived marital role	2/2
<u>Adult child carers</u>	
Keeping care in the family	5/5
Not knowing what it would be like	3/3
100% agreement	
$K = (Pa-Pc)/(1-Pc)$	
$K = (1-1/4)/(1-1/4)$	
$K = 1$	

**What factors play a part in the decision to continue caring for a family member with dementia?**

Identified themes	Agreement
<u>Spouse/partners</u>	
Relationship with care recipient	5/5
Support from others	2/2
<u>Adult child carers</u>	
Relationship with care recipient	2/2
Support from others	2/2

Lack of choice 2/2

100% agreement  
 $K = (1-.20)/(1-.20)$   
 $K = 1$

**What are the factors carers experience as most difficult to manage or stressful in caring for a family member with dementia?**

Identified themes Agreement

Spouse/partners

Behavioural aspects	4/4
Limitations	4/4
Emotional aspects	4/4
Change and loss	1/3

Adult child carers

Behavioural aspects	3/3
Limitations	2/3
Emotional aspects	3/4
Personality and relationship factors	5/5

86% agreement  
 $K = (.86-.125)/(1-.125)$   
 $K = 0.84$

The above was then re-calculated on the basis of combining the last two themes in the spouse/partner group, subsuming change and loss within the emotional aspects of care, to improve the agreement between raters.

Revised figure for agreement = 93%  
Revised Kappa co-efficient:  $K = (.93-.143)/(1-.143)$   
 $K = 0.92$

**What are the factors carers find most rewarding or satisfying in caring for a family member with dementia?**

Identified themes Agreement

Spouse/partners

Emotional/relationship	1/1
Normality/continuity	2/2

Adult child carers

Emotional/relationship	3/3
Self perception	3/3

90% agreement  
 $K = (.9-.25)/(1-.25)$   
 $K = 0.87$

**What are the factors carers associate with their perceived competence?**

Identified themes	Agreement
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Spouse/partners

Physical care	2/5
Practical care	2/2
Self concept	2/3

Adult child carers

Emotional care	3/3
Physical care	1/2
Practical care	3/3
Self concept	2/2

75% agreement  
 $K = (.75-.142)/(1-.142)$   
 $K = 0.71$

In order to increase the agreement rate between raters the top two themes in the spouse/partner group – physical and practical care – were combined and the figures were re-calculated as shown below.

Revised percentage agreement = 90%  
Revised Kappa co-efficient =  $(.9-.166)/(1-.166)$   
 $K = 0.88$

### STATEMENT OF INTEREST BY RESEARCHER

My interest in dementia pre-dates my clinical training. In my late teens I was main carer to my grandfather for a while – the family were not told he had vascular dementia at the time, but with the knowledge I acquired later it is clear that he had. I also worked as a nursing assistant in an NHS long stay unit for people with dementia prior to my clinical training. This latter experience played a major role in my motivation to train and work in clinical psychology, and I have worked in services for older adults for the last 8-9 years. During that time I have developed and extended my interest in services for people with dementia and their carers, both in direct clinical work and through service planning and evaluation.

My mother developed dementia some years ago and was cared for at home by my father until shortly before her death. This gave me personal experience of what it was like for both parties to be engaged in managing the effects of such a debilitating illness, as well as having my own perspective as daughter.

The original idea for my dissertation was concerned with exploring the experience of dementia, but with my mother's rapid decline and subsequent death I wanted to focus on an aspect of the condition that would be more emotionally manageable but still of interest and clinical relevance – hence the focus on caring. I did not know then that I would find myself in the caring role during the course of my research when my father's health declined and he was diagnosed with a terminal illness. I cared for him at home until his death, and found this both intensely stressful and intensely rewarding. I have tried to ensure that my personal experiences have not 'contaminated' my analysis and discussion of the data obtained in the course of this project, although they have obviously informed my thinking around the issues of caring.

**INTERVIEW TRANSCRIPT – GP**

22.1.99

**WHO DO YOU CARE FOR?**

My husband

**HOW LONG HAVE YOU BEEN CARING FOR HIM?**

His first illness was in 1988, but I haven't been a carer very long – since it became obvious he was suffering with dementia.

**WHEN WAS THAT?**

It's hard to say. It comes on so slowly. His incontinence became very bad in May 1997; we were staying with our daughter. It was very bad. I got in touch with the doctor and since then I have had help with protective clothing.

As for the date, I don't really know. It's getting harder now – I have to pace myself against the dreadful exhaustion. I can't be so fussy about the house anymore.

The last few months it has got quite hard on me.

**YOU LIVE IN THE SAME HOUSE...**

It's a flat actually.

**HOW DID YOU COME TO TAKE ON THE ROLE OF CARER FOR YOUR HUSBAND?**

His health started to deteriorate in 1988. He was taken to hospital and I think the doctor thought he had cancer of the prostate, which he didn't.

He went to the District Hospital one year later and after that was suffering with his leg – they called in "claudication". That seemed to get better. Then in 1997 when we were with our daughter, his single incontinence got much worse. He had dealt with it on his own till then and it wasn't a big deal.

A male nurse mentioned he was "senile". It was so foreign to me to talk about him like that.

**WHAT ASPECTS OF CARING FOR YOUR HUSBAND DO YOU FEEL YOU MANAGE PARTICULARLY WELL?**

All the physical things, you know. He has a good appetite and sleeps very well – better than I ever have – so from that aspect we're quite lucky. Those things I think I manage well.

**HAS YOUR SENSE OF COMPETENCE CHANGED OVER TIME?**

Yes it has. It has to. I am the one who has to see to everything. I have become a bit of a business woman. My husband is a potter, and I still get people coming for that. I have taken over. I've surprised myself at times.

**WHAT CHANGES IN YOUR SENSE OF COMPETENCE DO YOU EXPECT IN THE YEARS TO COME?**

I hope I carry on as I do now. As long as my health lasts – and I'm a fairly healthy person – I don't envisage any changes.

**DO YOU GAIN ANY PERSONAL SENSE OF SATISFACTION FROM CARING FOR YOUR HUSBAND?**

I am sure I do. Yes, yes.

**WHAT SORT OF THINGS GIVE YOU SATISFACTION?**

Just the fact that we're getting along, and I see that he is reasonably healthy. He goes out when it's nice weather – I encourage him to go – usually with my daughters, when they come, or my son, so I've got good support there.

**YOU GET SATISFACTION FROM KNOWING HE IS OKAY AND YOU ARE GETTING ALONG, AND THAT HE CAN GET OUT FOR A WALK. ARE THERE ANY OTHER THINGS THAT GIVE YOU SATISFACTION?**

Not really – just the fact that it is so. He doesn't do his pottery anymore, which is a sadness, but you can't bully him in to doing what they don't want to do.

**WHEN DID HE STOP HIS POTTERY?**

He hasn't done any in over 2 years.

**WHAT ARE THE THINGS YOU FIND MOST DIFFICULT TO MANAGE OR STRESSFUL IN YOUR ROLE AS CARER?**

Nothing really. I don't resent it, but I can't really get on with the things I'm interested in...

**LIKE?**

Study and things like that. I've always enjoyed studying languages and things like that. I'd love to continue, but there's no time, and when there is you are too tired. I do read though, in bed.

**THE MOST STRESSFUL THINGS ARE THE THINGS YOU CAN'T DO NOW?**

Yes, and the incontinence. I will have to get in touch with the male nurse to get him to talk to Fred. He is almost trying to say that he has a problem, and has been a bit lax. If he would just accept it and make the best of it...

WHAT, IF ANYTHING, ARE THE THINGS THAT HELP YOU CONTINUE IN YOUR ROLE AS CARER?

First of all, I have a good family and they are very supportive. And I want Fred to be able to go on and to be at home.

ARE THERE ANY OTHER THINGS I HAVEN'T ASKED ABOUT WHICH HAVE BEEN IMPORTANT TO YOU IN YOUR ROLE AS CARER?

I just need to contact the male nurse for help with the incontinence. I think he mentioned a laundry service, but I said I could manage. I could if Fred would co-operate, but it's this almost wanting to deny he has a problem.

MORE ADVICE AND SUPPORT FOR YOU BOTH ABOUT THE INCONTINENCE WOULD MAKE A DIFFERENCE TO YOUR LIFE.

I just can't talk to him about it. He gets a little bit upset and angry and throws things around a bit, and I can't cope with this as well as everything. That's why I often keep quiet, because it doesn't do anyone any good at all. It fills me with resentment and I think "I should be in a corner knitting or something..." not that I have ever done that.

IS THAT NEW, FOR YOUR HUSBAND TO GET A LITTLE BIT UPSET AND THROW THINGS AROUND?

No, that's happened before. It's part of his make up.

SO THERE ARE TIMES WHEN YOU'LL LET THINGS GO TO AVOID CONFRONTING YOUR HUSBAND AND HAVING THAT SORT OF THING HAPPEN?

Yes, quite.

## INTERVIEW TRANSCRIPT – MS

WHO DO YOU CARE FOR?

My husband.

HOW LONG HAVE YOU BEEN CARING FOR HIM?

Since he had a heart attack in 1988. In 1989 he had a triple by-pass. He had a cardiac arrest in the hospital on top of the heart attack at home, while we were waiting in the hospital. He'd had a heart attack at 49, but they let him go back to work, so we didn't think it was too bad. Then he had an infection after the operation and they had to open him up again... (tears). He was made redundant at 64, just before his second heart attack. When I look at the photos now I can see how ill he really was then.

It was after that he began to lose his memory. I mentioned it to the doctor – we were in Bracton then – and he said it may have been that the oxygen didn't get to his brain when he had his heart attack. The doctor wrote in support of us getting a downstairs flat, and we moved here 2 years later.

He's had strokes as well, three in the last 18 months. Twice he's been in to All Saints Hospital, but I didn't call the ambulance the last time 'cos I didn't think he was treated very well there. We waited eleven hours in Casualty.

After the last one the doctor said not to let him out on his own, 'cos he could just wander off. I used to lock the door and pop out quick for my shopping, but I can't do that now 'cos I don't know what he'll get up to, do I? He drank shampoo instead of medicine once, but the hospital said it wouldn't harm him.

HOW DID YOU COME TO TAKE ON THE ROLE OF CARER FOR YOUR HUSBAND?

Well, like I said before, it's happened bit by bit. Before he had the strokes I never thought of getting any help. We belong to a little club and we both enjoyed it, but now, his memory means he doesn't remember from half an hour ago.

DO YOU HAVE ANY HELP NOW?

No. They're trying to get one day's care, and my brother comes on Monday while I go to Sequence dancing and do my shopping. AG said I could get in touch with Help the Aged about the garden too.

WHAT ARE THE THINGS YOU FIND MOST DIFFICULT TO MANAGE, STRESSFUL OR FRUSTRATING IN YOUR ROLE AS CARER?

He doesn't want to do what I ask him to do – he seems very defiant. That's because of his memory, I suppose. He seems to think I'm nagging all the time. I try to do as AG said and go along with him, but you can't all the time. He goes back to when he had a lorry and says he has to go out and do that, but that was thirty years ago and I have to try and stop him going out. I've even taken him to the place he used to work



to show him it isn't there anymore. He says he wants to look for Maddy – that's me – and if I tell him I'm Maddy he says "no you're not, you're my sister..." and half an hour later he'll remember I am his wife.

Maybe I shouldn't, but I give him a whiskey before he goes to bed; just the one, like he used to have, and he enjoys it and I know I've got two or three hours on my own. It's a wicked thing and I feel guilty sometimes, but they said it was okay as long as it isn't in excess.

I haven't mentioned he's had TB for the last couple of years. They've just phased out the tablets. He's had a rough time. His feet aren't good either and he loses his balance and has lots of falls.

People don't know what you're going through at home, because they don't see. When we go to the club people say "Hello, John, how are you doing?" and he says "Fine" and they think he's okay and doing well.

**WHAT ASPECTS OF CARING FOR YOUR HUSBAND DO YOU FEEL YOU MANAGE PARTICULARLY WELL?**

Well, I mean, the bathing and washing his hair and I finish his shaving now for him, just finish in places where he hasn't got the strength of movement. I help him with things like that and I cope quite well with that. And meals and that – he never grumbles that he doesn't want to eat. And if we can get out a lot, that helps.

**SO YOU FEEL YOU MANAGE HIS PHYSICAL CARE OKAY.**

Yes. It's the mental pressure that is beginning to tell on me. Even when my brother comes on Monday I feel I can cope with the rest of the day, because I've had a break.

It's good to get him out, 'cos he doesn't think this is his home. When we go to the club he plays pool, and he hits the wrong balls but the others understand and don't say anything. He needs other people and he needs that sort of therapy. I've brought him puzzles and we used to do those, and he used to think that was quite good when we'd finished.

**HAS YOUR SENSE OF COMPETENCE CHANGED OVER TIME?**

Mine? I think so, really. I'm a little less competent, or else I wouldn't be asking for help. But then, he's got a lot worse. There were lots of things John used to do that I have to do now.

**WHAT CHANGES IN YOUR COMPETENCE DO YOU EXPECT IN THE NEXT YEAR OR TWO?**

I can't say, 'cos I don't know how bad John is going to get. I don't really know...

**DO YOU GAIN ANY PERSONAL SATISFACTION FROM CARING FOR YOUR HUSBAND?**

Oh yes. I wouldn't want him to go into a home or anything. I suppose that can come, if there's violence or anything like that. I can care for him alright.

SO THE FACT THAT YOU ARE CARING FOR HIM AT HOME GIVES YOU A SENSE OF SATISFACTION.

Oh yes. We've always been so close...

ARE THERE ANY PARTICULAR ASPECTS OF CARING THAT GIVE YOU SATISFACTION?

We've always been so close, it's knowing he's going this way that's the upsetting part, and I'll do all I can for him. We've always done everything together.

HOW LONG HAVE YOU BEEN TOGETHER?

Forty three years. We have a boy in Essex, but he has a high pressure job. They make them redundant so quickly now – he's a dealer in a bank – so he can't really take time off. He's got a mortgage and two little girls.

WHAT, IF ANYTHING, ARE THE THINGS THAT HELP YOU CONTINUE IN YOUR ROLE AS CARER?

Because I love him so much. I wouldn't want him to go anywhere else and I know he wouldn't have wanted that. I love him too much for that.

IS THERE ANYTHING I HAVEN'T ASKED ABOUT THAT HAS BEEN IMPORTANT TO YOU IN CARING FOR YOUR HUSBAND?

Well, until the last few strokes I never let anyone know I was a carer. If it had been the other way round I'm sure John would have done it for me.

I think the hardest thing is when they don't want your help. You say "I'm only trying to help you" and they say "I don't need your help". But they do. That's very hurtful.

INTERVIEW TRANSCRIPT: T.E.

WHO DO YOU CARE FOR?

My wife.

HOW LONG HAVE YOU BEEN CARING FOR HER?

She's had Alzheimer's Disease for 14 years, and I've cared for her for the last 12 years.

THAT'S A LONG TIME

A bloody long time.

DO YOU LIVE IN THE SAME PLACE?

Yes. She goes to Wells House (a residential and day care dementia service) on Monday morning and comes home late afternoon. She goes again Wednesday morning, sleeps over Wednesday and Thursday night and comes home Friday at about 6ish.

She's here at the moment while I get her urine infection sorted out, then I'd like her to go somewhere else... I'm not a great fan of Wells House. But I expect it will go on as usual.

WHAT IS IT YOU DON'T REALLY LIKE ABOUT WELLS HOUSE?

Well, it's a long story. She's been going there years and she's come back in the wrong clothes, dressed badly. I don't think the caring is up to standard, though it's got better than it was.

HOW DID YOU COME TO TAKE ON THE ROLE OF CARER FOR YOUR WIFE?

It's automatic, isn't it. I'm her husband, and as we found out about her forgetfulness and Alzheimers, then I took on the things she couldn't do. It's like an automatic switch over.

WHAT ARE THE THINGS YOU FIND MOST DIFFICULT TO MANAGE, STRESSFUL OR FRUSTRATING IN YOUR ROLE AS CARER?

Well, I mean... er... I've balanced it very well, I think, with her going to Wells House. The most stressful thing is being a prisoner in your own home. Thursday used to be my day off, that's what I used to call it – a day for doing my things. The rest of the week was for, well, her things. Without that time off I couldn't manage... it gives you something to look forward to. And it's helped Helen as well, 'cos it's helped keep me in a balance.

WHAT ASPECTS OF CARING FOR YOUR WIFE DO YOU FEEL YOU  
MANAGE PARTICULARLY WELL?

This might be boastful, but as far as I'm concerned I manage everything well. The washing, cooking, her care – I think I've coped over the course of time very well, as the situation has got worse.

DO YOU THINK YOUR SENSE OF COMPETENCE HAS CHANGED OVER  
TIME?

It's a gradual thing, and you change your ways. It's a gradual thing, you know? I used to give her a bath every morning and she used to jump in and enjoy it, and I'd have a bath too. Then she couldn't manage it, so I switched to the evening, 'cos she picked up in the day, and that was okay. But now she can't get in the bath at all, and I had to get a seat from the physio to get her in and out. That's just one example of how it changes and you have to change too.

(I've been) struggling to keep together this weekend. When she came home Friday she was like a drunk, legless. Usually we go out for a walk up the pond – do you know the pond up here? – but now if she stands up she's all wobbly and falls backward. Doctor said it may be the urine infection. It's been very sudden and you struggle to change. This is the first time it's happened like that. When there's something wrong Wells House just throw her back at me.

WHAT CHANGES IN YOUR SENSE OF COMPETENCE DO YOU EXPECT  
OVER THE YEARS AHEAD?

Well, it depends. Doctor said part of the confusion may be through the urine infection. It all depends if she can come back. I'm gradually getting with it and back in charge, but over the weekend I felt lost.

DO YOU HAVE ANY FAMILY OR FRIENDS YOU CAN TURN TO?

We didn't have family ourselves, no children. She has a sister in Manchester in a Home, and Swindon. I've got a sister and two brothers, but they're in their '80s and don't live near. My brother is blind, so he couldn't come, but the other would in a crisis. I can't rely on anyone in that sense.

DO YOU GAIN ANY PERSONAL SATISFACTION FROM CARING FOR YOUR  
WIFE?

Only when she smile. That's the only way I know she's alright. Nothing else. She doesn't know me, I think, but she's easy with me. It's hard to tell, they don't have no thoughts, do they?

WHAT, IF ANYTHING, HELPS YOU CONTINUE IN YOUR ROLE AS CARER?

I don't know. I mean, it's an automatic thing. She's looked after me in her time and now I look after her. There are times when I'd like to strangle her.

THERE ARE TIMES WHEN IT'S REALLY FRUSTRATING...

Yes, out of this world. It's the sheer frustration of ... the roles change... in the early days you can't believe such a lively person can change. You just can't believe it, even when you know it. The frustration and stress are the worst things and it's a long period of time.

WHAT HELPS YOU MANAGE THAT FRUSTRATION AND STRESS?

You just learn to accept these things. As it changes, you change too, and learn to balance it all out. I don't know if they all go down the same road; she's quiet and placid and always gives a smile. That helps, I suppose. Like everything else, if the problem's there you just have to cope with it. If they could transplant her brain, she'd be pretty good for her age, though she might not look it now.

IS THERE ANYTHING THAT'S BEEN IMPORTANT TO YOU THAT I HAVEN'T ASKED ABOUT?

I've had trouble which I shouldn't have had, I think. She lost her glasses and I had to get her eyes tested. I rang the Alzheimers Disease Society but there was no-one who could say this person can do it... specialists who are on call to do it. There should be something where you can go to be told okay, you can go here and they'll do it. Someone for ears, nose, throat, whatever. Not actually on call, not actually next door. There's a lack of practical information.

**INTERVIEW TRANSCRIPT: Z.B****WHO DO YOU CARE FOR?**

My husband.

**HOW LONG HAVE YOU BEEN CARING FOR HIM?**

More the last year. He's had problems two or three years back, but he isn't as bad as others I know.

**DO YOU LIVE IN THE SAME PLACE?**

Yes.

**HOW DID YOU COME TO TAKE ON THE ROLE OF CARER FOR YOUR HUSBAND?**

Just the need really.

**WHAT ARE THE THINGS YOU FIND MOST DIFFICULT TO MANAGE, STRESSFUL OR FRUSTRATING IN YOUR ROLE AS CARER?**

The most difficult thing is cheering him up. He gets terrible depressions. He's very aware of what's happening to him.

**DID HE KNOW HIS DIAGNOSIS FROM THE START?**

Oh, yes. I thought he was just not listening, but he knew.

**WHAT ASPECTS OF CARING FOR HIM DO YOU FEEL YOU MANAGE PARTICULARLY WELL?**

He's not in a position to want me to do things physically – he's able to wash, dress, shower for himself. I suppose I mother him. I treat him like a child in a way... he says I'm bossy.

**IS THAT DIFFERENT TO HOW THINGS WERE BEFORE?**

Oh, yes, yes. He's always been a bit dependent on me and I've been the stronger one, I've organised paying bills etc, which he paid for.

**DO YOU THINK YOUR SENSE OF COMPETENCE HAS CHANGED OVER TIME?**

I suppose I've become more competent through sheer necessity.

**IS THERE MUCH YOU'RE DOING NOW THAT YOU WEREN'T DOING BEFORE?**

I have to make more decisions now. The post comes in all the time and you have to make your own decisions. There's no point in saying "What do you think of this?"

WHAT CHANGES IN YOUR SENSE OF COMPETENCE DO YOU EXPECT IN THE YEARS AHEAD?

I suppose I'll become more like a nurse than a wife really. It's just what life dishes out and you get on with what you need to.

IT SOUNDS LIKE YOU ARE QUITE PHILOSOPHICAL ABOUT IT.

Yes I am, and I keep telling myself how lucky I've been and how lucky I am in relation to others.

DO YOU GAIN ANY PERSONAL SENSE OF SATISFACTION FROM CARING FOR YOUR HUSBAND?

I'd rather not! I suppose in a way, yes, maybe I do. I know I can – it sounds weird – there's a sense of satisfaction in knowing I am capable. I feel so sad for him.

WHAT IF ANYTHING ARE THE THINGS THAT HELP YOU CONTINUE IN YOUR ROLE AS CARER?

Once again, it was going to the carers group. It opened your eyes to the problem and you know it's not their fault. And just the fact that if I need help there'll be help.

DO YOU GET ANY HELP AT THE MOMENT, EITHER FOR YOU OR YOUR HUSBAND?

Just from the family. X (CPN) had an accident and has been off sick. Before that I saw her regularly. We saw Doctor A – do you know him? – he's very good and John likes him. We've got an appointment to see Doctor B. next week.

ARE THERE ANY THINGS I HAVEN'T ASKED ABOUT THAT HAVE BEEN IMPORTANT TO YOU IN CARING FOR YOUR HUSBAND?

There's a certain amount of frustration involved... the lack of freedom is hard. You're under pressure wherever you go. Like today, I went to lunch with some girlfriends and he rang to remind me. I want to accept invitations now because I may not get them later. It inhibits me, because I don't like to tell people. Close friends know and family of course.

WHAT'S THAT ABOUT?

Loyalty, I think. And I don't want them to treat him differently. I can't say I can't come (out) 'cos of Ian, if they don't know there's a problem.

IS YOUR HUSBAND BOTHERED BY IT IF PEOPLE TREAT HIM DIFFERENTLY BECAUSE THEY KNOW THERE'S A PROBLEM?

I don't think so. He tells people more than me. I think he wants them to understand that he's finding life difficult.

DO YOU THINK PEOPLE GENERALLY RESPOND SENSITIVELY TO THAT?

I think so. We both belong to the golf club, but he's told people there. X (CPN) said for goodness sake keep playing golf, but he can't score for himself. So he plays with people who can do that for him and tell him where he has hit his shot, some silly things like that. So people are kind. Maybe I should tell them more.



INTERVIEW TRANSCRIPT: MW.

WHO DO YOU CARE FOR?

Carol, my partner. We got together in 1979. In 1985 she had that accident – broke her leg and damaged her head.

WHAT HAPPENED?

She used to work in the bus garage in Edmonton. She was crossing a zebra and a police motor bike stopped for her, but a man in a car, an illegal immigrant I think, panicked when he saw the policeman and overtook, hitting Carol straight on. She copped the lot.

HOW LONG HAVE YOU BEEN CARING FOR HER?

Since the accident in 1985. Until then she was okay, working, cooking meals. She can't cook a meal now.

DO YOU LIVE IN THE SAME PLACE?

Yes, we live in a flat.

HOW DID YOU COME TO TAKE ON THE ROLE OF CARING FOR YOUR PARTNER?

I've been caring for her all the time. When they asked for the second brain damage (report) at the hospital in Hampton Hill, and the doctor asked who was the carer, they put me in touch with AG and she put me in touch with Pitt House, who gave me a carer's card.

WHAT ARE THE THINGS YOU FIND MOST DIFFICULT TO MANAGE OR STRESSFUL OR FRUSTRATING IN YOUR ROLE AS CARER?

I don't know. I do all the washing and cooking...there's not really anything...it's the same as bringing up the kids or anything. I just fell in to the role and do it. There's nothing I had to learn. Looking after always came natural like.

WHAT ASPECTS OF CARING FOR YOUR PARTNER DO YOU FEEL YOU MANAGE PARTICULARLY WELL?

Well, I've got to bath her and help her to get dressed, and, oh...it just comes as a second job to me. If you'd asked me years ago when it started like this, it was a bit of a job to know if you could do these things or not. I think once you accept what she's got, everything comes natural to you.

She can get to the shops if it's only one or two messages, but more than that and she gets confused. Same with that, you have to make sure she's got enough, to save her from getting confused.

HAS YOUR SENSE OF COMPETENCE CHANGED OVER TIME?

I don't think I can say much. Things are changing gradually, it doesn't seem to be a fast thing, but she's great. She knows herself and will go in to a fit of crying, you know?

WHAT CHANGES IN YOUR SENSE OF COMPETENCE DO YOU THINK YOU'LL FIND IN THE YEARS AHEAD?

Only looking at people in advanced stages, I'll say I'll have a lot more work with Carol. She'll not be able to get out. I don't have a picture of the future in mind, you just carry on day by day and hope for the best.

DO YOU GAIN ANY PERSONAL SATISFACTION FROM CARING FOR CAROL?

The way we met and got together, I don't get any personal gain from it, it's just things that come natural.

WHAT, IF ANYTHING, ARE THE THINGS THAT HELP YOU CONTINUE IN YOUR ROLE AS CARER?

I don't know how to really answer that. I love her, I do love her. It grew over the years. I wasn't going to take another woman – I had enough problems with the first. I suppose we got together through companionship and things just grow. And my children take to her...

Only thing is, I don't know how things are going to go this year. I have a private pension, and they've adjusted my tax code, so they're going to take more off me and I'm not sure how it's going to work out. I used to be a Shop Steward in the GLC and I'll go political and write to my MP when I know how it's going to be financially. As long as things work out financially as they are at present, we'll be alright. I save and we'll be going on holiday this year.

RESEARCH INTERVIEW: NJ.

WHO DO YOU CARE FOR?

My father.

HOW LONG HAVE YOU BEEN CARING FOR HIM?

About three years – since my mother died.

DID HE HAVE DEMENTIA BEFORE YOUR MOTHER DIED?

Yes. It wasn't obvious; it only became obvious after she died and I began to care for him on a full time basis. Looking back now, I think he's probably had it in a mild form for 10 years. I don't think mum would have recognised this, she'd have been outraged if someone said he had dementia. He's been in and out of hospital with his heart, and each time he came out there was less of him, if you know what I mean. Now I've come here (interview took place at a day hospital, where NJ does some voluntary work) I realise he had multi-infarct dementia, but I didn't know. He went down quickly in the first year after my mother died, and then after he was in hospital for a strangulated hernia – I think he must have had a major attack then, because he didn't recognise us for a week or more.

DO YOU LIVE IN THE SAME PLACE?

Yes. What happened was we were living in our own house and they were in theirs, but it was rented. They'd always lived there. At first I was walking round there, but it wasn't working, because he wasn't letting in people he should, like Meals on Wheels, and was letting in people he shouldn't. If I'd known what he was like I'd have had him in a Home, but I've been told that's not an option because he doesn't want it. So we bought the house and now we're all living together.

HOW DID YOU COME TO TAKE ON THE ROLE OF CARER FOR YOUR FATHER?

It was more or less forced upon me by circumstances and the law, basically.

WHAT ARE THE THINGS YOU FIND MOST DIFFICULT TO MANAGE, STRESSFUL OR FRUSTRATING IN YOUR ROLE AS CARER?

The lack of freedom. We can't have a holiday or go away or any of those normal things. Also my father's personality, regardless of the dementia.

You lose a normal way of life. I can't watch what I want on telly, because he doesn't like it or disapproves. I can go out for a few hours, but no more than that. I couldn't leave him for a whole day. And we have to go to bed very early to get any privacy.

He doesn't go the day care or respite, because he's got a very bad temper – he's a very difficult man, my father – and it just isn't worth it. You do things for an easy

life. When he has been in respite we've tended just to catch up with things in the house that we can't do when he's here.

#### WHAT ASPECTS OF CARING FOR YOUR FATHER DO YOU FEEL YOU MANAGE PARTICULARLY WELL?

I suppose the practical side: the housewifery bit, cooking and cleaning the home and that sort of thing. He's partially incontinent, but he can manage that. If he couldn't he'd have to go into a Home, 'cos I couldn't do that.

The only way to cope is not to think about it and get on with it. It's only talking to people like you or seeing normal people that I get upset and realise how abnormal I am.

#### HAS YOUR SENSE OF COMPETENCE CHANGED OVER TIME?

I suppose in some ways it's better, because I've had to cope with things I hadn't done before, like letting people in and that. I've met some very nice people because of the situation I'm in, strangely enough.

It's like he's the child and I'm the parent – it's like looking after a child all over again.

#### WHAT CHANGES IN YOUR SENSE OF COMPETENCE DO YOU EXPECT IN THE YEARS AHEAD?

That's a hard one. I don't know. I can't answer that. There are things I'd refuse to do – like if he needed nursing care. I know there are people who say they would take that on, but I can't. I've gone as far as I can. I've gone as far as I can cope with, let's put it that way.

#### DO YOU GAIN ANY PERSONAL SENSE OF SATISFACTION FROM CARING FOR HIM?

No, not really. I suppose I feel I'm doing a good job. From an outsider's point of view, people are always telling me how worthy I am, but that's not how it feels on the inside. It makes me feel grown up, looking after a parent. It's a different ball game to looking after a partner. If it was my husband I'd do anything I could for him, but when it's a parent, and one of the opposite sex, it's very difficult indeed.

#### WHAT, IF ANYTHING, ARE THE THINGS THAT HELP YOU CONTINUE IN YOUR ROLE AS CARER?

Well, I suppose we now live in a nicer house; I'm more comfortable at home than I was before, and that's a big plus. We know when my father does die we'll have a nice house to live in.

I've met a lot of nice friends through my father and my position, and I've learnt I can help other people in the same position, like I come here once a fortnight to help out.

That gives me a lot of satisfaction. I was more introverted, but I've had to come out of myself and it's done me good in that respect.

IS THERE ANYTHING ELSE THAT'S BEEN IMPORTANT TO YOU IN CARING FOR YOUR FATHER THAT WE HAVEN'T TALKED ABOUT?

I can't really think of anything, to be honest. I think we've covered most things.

## INTERVIEW TRANSCRIPT: WG.

## WHO DO YOU CARE FOR?

My father.

## HOW LONG HAVE YOU BEEN CARING FOR HIM?

A year; it depends what you mean by caring. My mother died twelve years ago. After she died he was very distressed and really didn't cope with it. She had cancer of the bladder and he couldn't cope with it. She was in and out of hospital for eight years and we thought that was what caused the problems at first. She refused to have her bladder removed, although she knew it was malignant, and when she finally agreed it was too late. She died ten days after the operation. Every time she went in to hospital he did things for her, like the kitchen or patio.

## DO YOU LIVE IN THE SAME HOUSE?

No.

## HOW DID YOU COME TO TAKE ON THE ROLE OF CARING FOR YOUR FATHER?

It's the usual thing. I've got two sisters, but I'm the only one who works part time. I get the impression their full time jobs are more important than their father. My sister in Scotland has been ringing for the last fortnight, because she realises he's not with it now, but he hasn't been for a while. They think if they ring him every day that's it, they've done their bit. My other sister is in Surrey – ten minutes away in her car – but she only takes him home once a month. She collects him on Friday, he stays the night, she gives him dinner and he's back at home by 9 o'clock. He tells me he doesn't tell her things because she just gets annoyed.

When we go on holiday my two daughters give him his tablets box. He hasn't got any reasoning ability – it's so easy to go down the box – but he gets in a muddle sometimes and gets it all wrong. I just hear how upset he is. I think he's better when he goes to Scotland, because they used to think if you bullied someone they'd try harder... they didn't realise he's already trying his best.

I hadn't worried about his financial business, because his work pension is paid in to his bank account, and all his bills are on direct debit. His state pension covers food and incidentals, and now he has attendance allowance, so it's building up a bit. I'm in a quandary about whether to get private help in, because his nurse from the surgery won't do any more.

I spoke to him this morning about the money and how the three daughters can have their names on it. He agreed. I tried to explain it all to him, but I'll have to do it ten times for it to go in. He's more worried about the man he thinks is living in his house.

The main problem is that no-one offers anything, If I want to have something I always have to ask and stamp my foot and get angry. I think like most carers you don't want to make a fuss.

#### HOW OFTEN DO YOU SEE YOUR FATHER?

All day Sunday, sometimes on a Monday, it depends on , well, it's not a promise that I'll see him Monday. My husband has problems with his health at the moment and I like to go to his hospital appointments too. My father has a cleaning lady in on Mondays, so that's like company for him. Tuesdays I work, and I can't go to him straight from work because I do bell ringing. Wednesday he goes to Cardinal House, which frankly he's not keen on. He's been going there about eight months. They say he seems to enjoy himself. I think it upsets him that the other people go to sleep as soon as they get there, but I think it's becoming the norm for him now. He says the activities are much too childish, but he does get a good dinner. Thursday he goes to the Alzheimers Club, he gets picked up and gets his dinner, I go there from work and spend the afternoon with him there. I go back to his house after and that's when I get all the jobs done – clean the toilets, change his bed, take his socks for washing because he can only use one programme on his washer-dryer. His drawers are in a mess, nothing's where it should be. I get his ironing done. He sits down and goes to sleep and that's when I crack on with things. I think he's frightened of ironing now. He maintains his new ironing board is wobbly, but I think he's afraid.

Friday I phone him and sometimes I'll meet him for lunch. It depends on how he seems on the Thursday – if I think he can do without, then I don't. Friday is also Warfarin day , so every third Friday I'd see him. And he sees quite a few Specialists for things, so I have to go to every appointment with him. That means I have to take little bits of time off work, and now he gets attendance allowance I get him to pay me what I lose from my wages.

Saturday I don't see him, and I wait for the phone calls. I get about five a day, sometimes saying what he's just told me.

I wonder if the man is the Meals on Wheels person?

He really enjoys the Alzheimers club, although he didn't yesterday because the carer at our table made them play dominoes the right way, all the rules, and he just got fed up with it.

#### WHAT ARE THE THINGS YOU FIND MOST DIFFICULT TO MANAGE OR STRESSFUL IN YOUR ROLE AS CARER?

I think it's the phone calls.

#### WHY IS THAT?

Well, he's always got a problem that isn't a problem. I phone him every day to tell him what day it is, whether he needs to stay in, or whatever. He has a board where I put it all in big writing. If I say it often enough he can meet me – he can meet me in the cafe at Tesco, but if I change the time or the place, we've had it. I changed it from

ten to half past nine the other week, because I had to meet friends for lunch and we went over it so many times. At ten o'clock Tesco's not busy. He used to have a cup of tea, but he doesn't anymore. He just sits, and as you approach that vacant look is there.

(Showed me a photo of her father and one at christmas with her sister in Scotland)

I know I sound very resentful, but I feel that way today. Sometimes I feel I'm going the same way as him, when I can't remember things.

**DID YOU KNOW THAT FEELINGS CAN EFFECT YOUR MEMORY AND CONCENTRATION?**

Do they? I didn't know that. I don't want him to feel useless, that's one reason I don't have him to live with me, because I know he'd go right down. That's not all though. He already occupies most of my time. I have two daughters and the oldest one's had a lot of troubles with her husband leaving her, so I've had all that to cope with as well. If he was here I'd have no time for them as well.

**WHAT ASPECTS OF CARING FOR YOUR FATHER DO YOU FEEL YOU MANAGE PARTICULARLY WELL?**

I feel I've got his complete trust and he feels he can tell me everything, which he does.

**SO THE RELATIONSHIP IS GOING WELL. DO YOU THINK YOUR SENSE OF COMPETENCE HAS CHANGE OVER TIME?**

No. I think I've learnt to be more competent. At the outset you can't believe you'll be able to cope with all this.

**WHAT CHANGES IN YOUR SENSE OF COMPETENCE DO YOU ENVISAGE IN THE YEARS TO COME?**

The years to come? I suppose I shall expect to be totally taking over his affairs.

**DO YOU FEEL MORE COMPETENT AS HIS CONDITION GETS WORSE?**

I don't know really. I think its got to be easier once they're less in this world, if you know what I mean. You can say what'll happen and there'll be no questioning your decisions. In a way its good for him to question me about Meals on Wheels, or the cleaning lady. If you're talking to a zombie you don't have to explain things, do you? I suppose I'm happier that atleast my sister in Scotland is more interested, so I can unload on her now and and I see that in the future it won't just be me, I can tell her too, and that'll give me a bit of a boost, because my younger sister just wants to put him in a Home. She says it in the kindest way. She just thinks dad is ruining my life, which in some way is true, but I love him. She says at the end of the day you have to say you can't do any more. I think X (CPN) will tell me when I get to that stage.



DO YOU GAIN ANY PERSONAL SENSE OF SATISFACTION FROM CARING FOR YOUR FATHER?

Yes, I think so. When he says things like "I hope I'll be coming to you for Sunday dinner, 'cos you make a lovely dinner." He's always thanking me. I imagine when he talks to my sisters he's sick of hearing how wonderful I am!

And I can boost him sometimes. He was very down the other day and said I should put him in a Home, and I could say "Well, no, when I came round on Thursday I was very impressed. You'd done your washing, got something in for your tea..." I think he relies on me praising him. I can build his confidence. That's something I'm quite good at.

WHAT IF ANYTHING ARE THE THINGS THAT HELP YOU CONTINUE IN YOUR ROLE AS CARER?

Basically I'm a Christian, and I know there are people praying for me, and I find that very comforting. I think it sets a standard for yourself, to always be kind to him. Very rarely am I snappy with him, unless he really won't listen. I mean, no-one's perfect, we've all got to occasionally let go. And it's a help that my sister rings me now.

And the biggest help is my husband. I couldn't manage without him. He isn't a Christian, but he's a really lovely man.

**INTERVIEW TRANSCRIPT – M.E.**

**WHO DO YOU CARE FOR?**

My mother.

**HOW LONG HAVE YOU BEEN CARING FOR HER?**

Just the last year. She has been very independent and self sufficient till last January. She had a fall in the road and had to rest her leg for two months, and just as she was getting back on her legs she fell off a table and broke her leg. She was in hospital for four weeks then had the District Nurses coming in. I think staying in hospital increased her dementia – she was more confused and disorientated. The dementia became apparent about three years ago.

**DO YOU LIVE IN THE SAME PLACE?**

No. She has her own flat. I see her two to three times a week, and spend about an hour each time.

**HOW DID YOU COME TO TAKE ON THE ROLE OF CARER FOR YOUR MOTHER?**

There's just my sister and I. She lives in Hampshire, so it's more difficult for her. She tries to visit every week, and shares in taking her to hospital appointments. She is very supportive. It was just the luck of the draw that I happened to be nearby.

**WHAT ARE THE THINGS YOU FIND MOST DIFFICULT TO MANAGE, STRESSFUL OR FRUSTRATING IN YOUR ROLE AS CARER?**

Trying to persuade her that certain ways of doing things would be to her benefit. Hygiene, safety in the home – a spectrum of things. We try to talk calmly to her, but I end up shouting. She agrees and then it reverts back. There's no way of approaching her – it's like we're on two different wavelengths.

**IS THIS A CHANGE FOR YOUR MOTHER?**

No, it's part of her personality. She has always liked to be in control and is quite stubborn.

**WHAT ASPECTS OF CARING FOR YOUR MOTHER DO YOU FEEL YOU MANAGE PARTICULARLY WELL?**

That is difficult. Every time I go I end up arguing.

I think just the contact. She tells me how much it means to her and I know it brings her a lot of pleasure. I find it all very embarrassing.

**WHY EMBARRASING?**

Because of the relationship we had before. I was brought up with no love and hugs and we never talked about how we loved each other. And I'm still hurt that she accused me of taking things from the home – there is a lot of anger there.

MMM...?

She senses a deterioration in the relationship. She said when we were in hospital that we used to be very close – like sisters – I never remember that! She was very supportive when I was younger, she helped with the children, and I owe her a lot, but I do feel very hostile and it surfaces in conversation.

HAS YOUR SENSE OF COMPETENCE CHANGED OVER TIME?

Well, I don't give any hands on care as such. I suppose it has increased, because not only do I work and run my own home, I do a lot for her too – juggling hospital appointments, paying her bills, her medication, changing arrangements for Meals on Wheels etcetera. Five years ago I would have thought 'I can't do all that!' She cared for me and the roles are reversed now.

WHAT CHANGES IN YOUR SENSE OF COMPETENCE DO YOU EXPECT IN THE YEARS TO COME?

I might be expected to take on more and I find that frightening. It's not an issue I look into too deeply – fear of the unknown and how it will effect my life.

YOU TAKE IT DAY BY DAY?

Yes, yes.

DO YOU GAIN ANY PERSONAL SATISFACTION FROM CARING FOR YOUR MOTHER?

No.

WHAT, IF ANYTHING, ARE THE THINGS THAT HELP YOU CONTINUE IN YOUR ROLE AS CARER?

The fact that my sister shares with me. And there isn't anyone else if I don't do it – lack of choice.

ARE THERE ANY THINGS THAT HAVE BEEN IMPORTANT TO YOU AS A CARER THAT I HAVEN'T ASKED ABOUT?

I can't think of anything off the top of my head.

(We then went on to discuss her anger with her mother in more detail and I suggested ways of understanding how her mother could have thought ME had taken things from the home.)

**INTERVIEW TRANSCRIPT: EB (PILOT)**

**WHO DO YOU CARE FOR?**

My mother.

**HOW LONG HAVE YOU BEEN CARING FOR HER?**

Two years.

**DO YOU LIVE IN THE SAME HOUSE?**

Yes.

**HOW DID YOU COME TO TAKE ON THE ROLE OF CARING FOR YOUR MOTHER?**

(Laughs)... Mum lived in the States with my father and sister. Dad died about seven years ago. My sister also has a severely autistic son, who is fifteen and extremely difficult to cope with. She couldn't cope with mum anymore, but we didn't want to put her in a Home, so I said I would do it. I remembered the mum I used to have, not the one I have now. So I got on a plane and went to The States to collect her, and found the confused old woman who needs total care.

**IT SOUNDS AS IF IT WAS QUITE A SHOCK FOR YOU...**

Initially I was coping, although I was working from home, but as the months went by I realised she wasn't going to get any younger or any better. If I had known, I wouldn't have taken it on. My sister had coped for fifteen years, and we thought she was just old and forgetful..We didn't know she had dementia.

**WHAT ASPECTS OF CARING FOR YOU MOTHER DO YOU FEEL YOU MANAGE PARTICULARLY WELL?**

Physical? I don't know. I think someone has to tell me that. I just do the best I can. I think she's utterly spoilt. She is well fed and clothed, warm and comfortable. She's very annoying...

OH?

Mmm...

**HAS YOUR SENSE OF COMPETENCE CHANGED OVER TIME?**

My tolerance and my patience have become a lot worse. I think I'm doing just as well.

**WHAT CHANGES IN YOUR SENSE OF COMPETENCE DO YOU EXPECT IN THE YEARS TO COME?**

My competence is linked to my physical health – I have a bad back and had an accident just over a year ago, so as mum needs more lifting and moving I won't be able to. I was a paediatric nurse manager and back ache is part of the job, but I took early retirement and I'm more conscious of it now. I do more lifting at home.

DO YOU GAIN ANY PERSONAL SENSE OF SATISFACTION FROM CARING FOR YOUR MOTHER?

I never really thought about it. At the end of the day, I don't find it very satisfying. There are other things I could do to give a sense of satisfaction. I just do it.

WHAT ARE THE THINGS YOU FIND MOST DIFFICULT TO MANAGE OR STRESSFUL IN YOUR ROLE AS CARER?

The fact that I have to do things every day like get up early in the morning even if I feel like lying on. She goes to Day Centre three times a week, which I should be grateful for. The limits on my time.

WHAT IF ANYTHING ARE THE THINGS THAT HELP YOU CONTINUE IN YOUR ROLE AS CARER?

Oh dear...mmm...I have to, I suppose, because there's no-one else to do it.

LACK OF CHOICE?

Yes.

ARE THERE ANY OTHER THINGS I HAVEN'T ASKED ABOUT WHICH HAVE BEEN IMPORTANT TO YOU AS YOUR MOTHER'S CARER?

Lack of information. I didn't know where to begin. I went to the GP because I thought there was a problem with mum, but it was a friend at work who said I could apply for financial help. It was all piecemeal.

It would have been good to find an Asian organisation, because my mother is the only one in her group. She has regressed to her childhood and looks around for her parents and family, but she doesn't see any familiar faces. I think if she had more Asian people with her she wouldn't be so quiet and just sit there.

I also feel a lot of anger and irritability, and then I feel guilty if I shout at mum for asking the same questions again and again. And I look after my grand-daughter during the day too, so there's little break for me from caring.

INTERVIEW TRANSCRIPT: H.S.

WHO DO YOU CARE FOR?

My mother.

HOW LONG HAVE YOU BEEN CARING FOR HER?

I was caring for my mother and father until my father went in to a Home; he had dementia and I was caring for him. I probably didn't realise she needed the help too, because she could get up and down stairs alright. It's been about 5 years altogether and about 2 years in August just for my mother. That's when my dad went in to hospital and then from there he went in to a Home.

DO YOU LIVE IN THE SAME HOUSE?

Yes.

HOW DID YOU COME TO TAKE ON THE ROLE OF CARER FOR YOUR MOTHER?

Living here, I just naturally... you just naturally do it. This is my family home.

WHAT ARE THE THINGS YOU FIND MOST DIFFICULT TO MANAGE, STRESSFUL OR FRUSTRATING IN YOUR ROLE AS CARER?

Well, I cope with the washing and that alright, but I think it's the going out. She asks when, you feel guilty if you know what I mean. She keeps saying, all the days you're going out, she goes on all through the week. So I go out to darts tonight and stay with a friend, but I'm back first thing to do her breakfast, and she says, "So you're out tonight, but you'll be back first thing, won't you?" And I say "You don't mind, mum, do you?" And they have a way of making you feel guilty. I don't want to give in to that part.

WHAT ASPECTS OF CARING FOR YOUR MOTHER DO YOU FEEL YOU MANAGE PARTICULARLY WELL?

I think I manage alright, it's just that part that I've told you...

HAS YOUR SENSE OF COMPETENCE CHANGED OVER TIME?

What do you mean? How competent you feel as a carer? Well, it's just I get depressed sometimes... Whether she's making me feel guilty or whether it's just me. I mean, I take her twice a week to see my dad in the Home, and twice a week I take her to the day centre. When dad was home I used to wheel her out, and she used to say, "let dad push," but he wasn't well, so he couldn't. But I had a heart operation when I was 35, and 5 years ago they said I may need a two-valve replacement, but it hasn't got any worse. Other people get a lot of problems and pain, but I've got to be fair, I haven't. Sometimes, like Friday, she'll pretend she's sick, and I get annoyed,

because on Fridays I go out. I stayed in for her the other week, but then I thought, "no, if I give in, she's going to play on that".

You see, she likes to go out, but we haven't got a car, I just wheel her out. We stay three, three and a half hours with my dad, but I take a cab. She doesn't do bad really, but she's one of these old people that like to go out.

DO YOU FEEL MORE COMPETENT THAN WHEN YOU BECAME HER CARER OR LESS SO?

I think less so than at first. I used to get out more. Now I feel guilty.

WHAT CHANGES IN YOUR SENSE OF COMPETENCE DO YOU EXPECT IN THE YEARS AHEAD?

I don't really know.

DO YOU GAIN ANY PERSONAL SENSE OF SATISFACTION FROM CARING FOR YOUR MOTHER?

Yeah. I'm satisfied with what I do, it's just that part, again, that worries me.

WHAT SORT OF THINGS GIVE YOU PERSONAL SATISFACTION?

Oh, I'm satisfied in a sense, looking after her and that. I'm glad I can do it really, I just get upset over them other parts.

WHAT, IF ANYTHING, ARE THE THINGS THAT HELP YOU CONTINUE IN YOUR ROLE AS CARER?

Well, because she's pleased. She's glad I'm here looking after her and that.

She eats alright and them kind of things. It's just I feel guilty when I go out.

When I'm getting her ready to visit my dad, or go to the day centre, because I know she's enjoying it.

When my dad was here he could get up and go out, but she can't. She can just walk from here to next door (room), but apart from that she has to have somebody to help.

IS THERE ANYTHING I HAVEN'T ASKED ABOUT THAT'S BEEN IMPORTANT TO YOU AS A CARER?

No, no. I think you've asked all.

INTERVIEW TRANSCRIPT; MP.

WHO DO YOU CARE FOR?

My mother

HOW LONG HAVE YOU BEEN CARING FOR HER?

She's been in London since 1983, so that's, what – 16 years? But if you're asking how long she's had dementia it's 5 or 6 years now.

WHAT KIND OF CARE DID YOUR MOTHER NEED FOR THE FIRST 10 YEARS?

Quite a lot of support. We both belonged to a choir, for example. My mother has never been the kind of person to do things on her own. She's always sought support from myself and my sister with things like that. She could go shopping, but she didn't. She went to lip-reading classes on her own, which was good, but apart from that she is very much a family person. She relies on the family for entertainment and support. For life really.

DO YOU HAVE OTHER FAMILY LIVING IN THE AREA?

Yes. My sister came to London at the same time as my mother, and she lives at the Common - she retires in May - and my mother's grand-daughters live in Shenfield and Brighton, so that's her family really.

DO YOU LIVE IN THE SAME HOUSE?

My mother has her own little flat in Park Hill. A little one bedroom flat, just two – hers and the one underneath. She's lived there since she came to London and has always felt safe there until recently. Now she imagines people come in in the night, but that's part of her illness. She did feel safe there.

HOW MUCH TIME DO YOU SPEND WITH YOUR MOTHER?

Well, she goes to Pitt House now 5 days a week, so now I'll see her 3 evenings a week and sometimes on a Saturday.

BEFORE PITT HOUSE IT WAS DIFFERENT?

Yes, I went round most days for the afternoon or the morning. it didn't matter which . At some time.

YOU USUALLY GO THERE?

Yes. My mother goes to my sister every Sunday. I used to have her over for lunch or tea, just for a change, but since Pitt House it's changed. We found now she's not



happy out of her own flat. She used to stay with my sister sometimes, because she has the accomodation, but now she gets distraught if she's not at home.

HOW DID YOU COME TO TAKE ON THE ROLE OF CARER FOR YOUR MOTHER?

Well, I think it happens. (I laugh because it sound implausible, but that's how it happened...) When I was eight my father went to the war, and my sister was two. And he looked me straight in the eye and said "Take care of your mother" and I have always taken that on. In reality not, because my father returned from war, and didn't die till 1979, and my mother has been more dependant on my sister and myself since then.

SO YOU REALLY TOOK YOUR FATHER'S MESSAGE TO HEART?

Yes, I did, I did. I'm just beginning to kick it. I had a quadruple heart by-pass four years ago, and the angina symtoms have come back. I'm not feeling good right now. Not good at all. I'm trying to rein back now and separate more from my mother, because I have to, and if not she could survive me and my sister. My mother as been a creaking gate healthwise – do you understand what I mean by that? – all her life, but she's actually very tough.

WHAT ARE THE THINGS YOU FIND MOST DIFFICULT TO MANAGE, STRESSFUL OR FRUSTRATING IN YOU ROLE AS CARER?

I think the most difficult things are to do with bodily functions in a way. In other words, eating or not eating. She's incontinent now, and is beginning to be doubly incontinent, and I find that very difficult. I find it stressful to spend much time with my mother now, so I do it in short bursts. I find her life-long pessimism quite difficult, although, heaven knows, at her stage of life she has reasons to be pessimistic, but I find it hard to cope with and always have.

Her argumentativeness...

IS THAT NEW?

No, it's a continuation, and it's better than it used to be. Because she's more frail it's harder for her to sustain. What seems to have happened is that through the condition her personality traits or characteristics have all got exaggerated. So she's kinder now than she's ever been, and her sense of humour is better. We laugh more now than we've ever done. So it's the positive and negative and I think its important to say that.

WHAT ASPECTS OF CARING FOR YOUR MOTHER DO YOU FEEL YOU MANAGE PARTICULARLY WELL?

Hmm... I think I'm able to provide boundaries and structures for her. When she gets paranoid or... umm..obsessional about things, I think I'm able to talk to her about it and make it less powerful, less threatening, something like that. Defuse it. I think

that's what I do best. I'm not good at physical things, at things that require touch. I think she trusts me, even in her confusion.

SO THE EMOTIONAL SIDE IS SOMETHING YOU FEEL BETTER AT, AND NOT THE PHYSICAL OR PRACTICAL SIDE OF CARING?

Yes, quite. And my sister is better at the physical and practical side than me – I won't say she enjoys it.

HAS YOUR SENSE OF COMPETENCE CHANGED OVER TIME?

My sense of competence has changed in that I feel less able to cope.

WHY LESS ABLE TO COPE?

Yes, I'm just thinking about that. I used to take it in my stride, and go to my mother and just do what needed doing, but now they bother me. In the past I would have dealt with things and it would have been alright; now I feel less able. And I feel sad about that.

DO YOU THINK THAT IS MORE DUE TO CHANGES IN YOUR MOTHER OR IN YOURSELF?

I think it's both really, and they run in parallel. I've never thought of it before, but they do. As she becomes more and more frail and confused I become more and more less able to cope.

WHAT CHANGES IN YOUR SENSE OF COMPETENCE DO YOU EXPECT IN THE YEARS AHEAD?

Not many, I hope! I don't want to feel much less competent than I do now. Umm... I think I will probably feel less physically competent in the years ahead, umm..I mean, I hope I won't feel less emotionally, intellectually, whatever, competent, but I could.

I alternate between hoping that my mother will die, and feeling bad about that, 'cos I just... I'm struggling.

HOW LONG HAVE YOU BEEN FEELING LIKE THAT?

That I'm struggling? Getting on for a year, I suppose. I think if my mother had not been able to go to Pitt House Monday to Friday, then I wouldn't be coping. She loves it. And someone else takes the responsibility, that's the major thing. I know that while she's there they'll take care of her and look after her – and that's a terrific feeling.

And my sister says, "Don't take these things so seriously! Just go (blows) and blow it away." But we're very different, I deal with my stress by writing, I write about my work mainly, but I deal with my stress by writing a book on stress. And it helps; it helps me to feel competent.

## WHAT KIND OF WORK DO YOU DO?

Counselling. I wrote a book in 1974, and vowed I'd never do it again. But I enjoy it now. So I'll think about you writing up your dissertation.

## DO YOU GAIN ANY PERSONAL SENSE OF SATISFACTION FROM CARING FOR YOUR MOTHER?

Not a lot. It feels like a burden. It feels like a duty. It just seems to have been going on for so long. I mean, I've been taking her last year to the Age To Age reminiscence project, and I enjoyed that. We both did. And it was great to see her with other people, because she's different – we all are. And I did enjoy that and get a sense of satisfaction from that. And it's the same with the choir, although I haven't taken her since Christmas. She can still sight read the music, but she can't manage the repeats and second verses. She does some singing there (at Pitt House).

And I get satisfaction from the fact that other people like my mother. It's the same at Pitt House as in the choir, she interacts well and they always ask after her. I threw a big party at Heather House for her 90<sup>th</sup> birthday, and the choir came and sang. I put a three line whip on it for the family and they all came, played instruments, sang, recited a poem. And when I went to see her the next day she said "What you did yesterday, it was good." And, you know, that's the first time she's ever said that. It was a great party.

## WHAT, IF ANYTHING, ARE THE THINGS THAT HELP YOU CONTINUE IN YOUR ROLE AS CARER?

Well, something helps me continue, 'cos I do. Undoubtedly one of the things is duty. And... she's my mother. I don't love her, but I like her better than I used to, so I think that helps. I feel for her. I dare not get in touch with what it must be like for her...it must be so confusing and frightening to be in her head. And in my work I have helped people get in touch with things as painful as that, but I can't do it now and I can't do it for her.

But the knowledge that it is difficult is one of the things that keeps me going. I know it's hard for her and I want to do what I can. But I don't want it to kill me.

## **1. Spouse/partner carers**

The following section gives details of the themes and sub themes identified in Table 6, with examples from the interview transcripts.

### **Main theme – care recipient**

#### **Sub theme – dementia**

This sub theme was itself made up of a number of different aspects:

Onset: MS talked about the first signs of her husband's dementia thus, 'It was after that he began to lose his memory. I mentioned it to the doctor – we were in Bracton then – and he said it may have been that the oxygen didn't get to his brain when he had his heart attack'(1.10).

Behavioural manifestations: MW said of his partner 'She can get to the shops if it's only one or two messages, but more than that and she gets confused' (1.31).

Insight: ZB said 'The most difficult thing is cheering him up. He gets terrible depressions. He's very aware of what's happening to him' (1.13).

#### **Sub theme – physical health**

A number of the care recipients had concurrent poor physical health, either of a chronic or acute nature. MS's husband had a history of multiple health problems dating back to a heart attack in 1988. She said 'In 1989 he had a triple by-pass. He had a cardiac arrest in the hospital on top of the heart attack at home...' (1.4) and later 'He's had strokes as well, three in the last eighteen months' (1.14).

#### **Sub theme – loss and change**

This theme came up in different ways, relating to previous interests, aspects of the personality and a more general, pervasive sense of loss relating to the care recipient. For example, GP said 'He doesn't do his pottery anymore, which is a sadness, but you can't bully him in to doing what they don't want to do' (2.26). And TE said '...in the early days you can't believe such a lively person can change. You just can't believe it, even when you know it' (3.1).

#### **Sub theme – social contacts/support**

ZB had been talking about her reluctance to tell others of her husband's dementia, saying she did not want people to treat him differently. When asked if her husband was bothered if people treated him differently she said 'I don't think so. He tells people more than me. I think he wants them to understand that he's finding it difficult' (3.1).

### **Main theme – care provider**

#### **Sub theme – coping**

This sub theme incorporated a number of different aspects of coping, including strategies, ways of managing behaviour, limitations and adapting to the changes that the illness brings.

Strategies: TE demonstrated a practical coping strategy, saying 'Thursday used to be my day off, that's what I used to call it – a day off for doing my things. The rest of the week was for, well, her things. Without that time off I couldn't manage...it gives you something to look forward to' (1.28). MW said 'I think once you accept what she's got, everything comes natural to you' (1.29).

Managing behaviour: This related to attempts by carers to manage the dementia related behaviour of their dependant, usually of a problematic nature. MS, talking

about the impact of her husband's memory impairment, said 'He goes back to when he had a lorry and says he has to go out and do that, but that was thirty years ago and I have to try and stop him going out. I've even taken him to the place he used to work to show him it isn't there anymore' (1.34).

**Limitations:** The demands of caring placed a number of restrictions or limitations on the carers. MS said 'I used to lock the door and pop out quick for my shopping, but I can't do that now 'cos I don't know what he'll get up to, do I? He drank shampoo instead of medicine once...' (1.18).

**Adapting to change:** This related to the process by which carers adapted to changes brought about by their dependant's dementia. TE said 'It's a gradual thing, and you change your ways. It's a gradual thing, you know? I used to give her a bath every morning and she used to jump in and enjoy it, and I'd have a bath too. Then she couldn't manage it, so I switched to the evening, 'cos she picked up in the day, and that was okay. But now she can't get in the bath at all, and I had to get a seat from the physio to get her in and out. That's just one example of how it changes and you have to change too' (2.6).

#### Sub theme – physical and practical impact of caring

GP said 'It's getting harder now – I have to pace myself against the dreadful exhaustion. I can't be so fussy about the house anymore' (1.10).

#### Sub theme - Emotional impact of caring

MS said '...It's knowing he's going this way that's the upsetting part, and I'll do all I can for him' (3.8).

#### Sub theme – social support

Carers obtained social support from a number of sources, including their families. ZB had been to lunch with friends on the day of our interview. She said 'I want to accept invitations now because I may not get them later' (2.27).

#### Sub theme – models of care

Several carers volunteered a model to understand their new role; for example, ZB reflecting on what she does for her husband, who does not yet require physical care, said 'I suppose I mother him. I treat him like a child in a way... he says I'm bossy' (1.20).

#### Sub theme – self concept and competence

When asked about those aspects of care he thought he managed particularly well, TE replied 'This might be boastful, but as far as I'm concerned I manage everything well... I think I've coped over the course of time very well, as the situation has got worse' (2.1).

#### Sub theme – the future

Several carers made comments about how they saw the future. MW said '...Looking at people in advanced stages, I'll say I'll have a lot more work with Carol. She'll not be able to get out. I don't have a picture of the future in mind, you just carry on day by day and hope for the best' (2.6).

#### **Main theme – the relationship between the care provider and the care recipient**

This theme emerged from a number of the individual analyses. For example, MW said 'I love her, I do love her. It grew over the years... I suppose we got together through companionship and things just grow' (2.15).

## **Main theme – services**

### **Sub theme – services received**

ZB recounted the input she had received from the local community mental health service: 'X (CPN) had an accident and has been off sick. Before that I saw her regularly. We saw Doctor A – do you know him? – he's very good...' (2.20).

### **Sub theme – shortcomings of services**

Talking about an apparent acute infection that had markedly worsened his wife's confusion and mobility, TE said 'When there's something wrong Wells House just throw her back at me' (2.16). GP, commenting on the diagnosis of her husband's dementia, said 'A male nurse mentioned he was "senile". It was so foreign to me to talk about him like that' (1.31).

## **2. Adult child carers**

The following section gives details of the main themes and sub themes that emerged from the analyses of the adult child carers' transcripts, summarised in Table 6.

## **Main theme – care recipient**

### **Sub theme – dementia**

This sub theme included onset of the dementia, behavioural manifestations and issues of loss and change relating to it.

Onset: NJ said 'Looking back now, I think he's probably had it in a mild form for 10 years' (1.7).

Behavioural manifestations: MP described how her mother had her own flat nearby, 'She's lived there since she came to London and has always felt safe there until recently. Now she imagines people come in in the night, but that's part of her illness' (2.20).

Loss and change: WG described how she would meet her father in the local town in Tesco's café, 'At ten o'clock Tescos is not busy. He used to have a cup of tea, but he doesn't anymore. He just sits, and as you approach that vacant look is there' (3.2).

NJ said 'He's been in and out of hospital with his heart, and each time he came out there was less of him, if you know what I mean' (1.9).

### **Sub theme – continuity/personality**

This sub theme related to aspects of the care recipient that represented continuity of personality rather than change. For example, MP said of her mother 'I find her life-long pessimism quite difficult, although, heaven knows, at her stage of life she has reasons to be pessimistic, but I find it hard to cope with and always have' (2.23). And NJ, when asked about stresses, said of her father '...Also my father's personality, regardless of the dementia' (1.29).

## **Main theme – care provider**

### **Sub theme – coping**

As with the spouse/partner group, this sub theme incorporated a number of different aspects of caring, including strategies, understanding the behaviour and managing the behaviour.

Strategies: NJ gave an example of this, saying 'The only way to cope is not to think about it and get on with it. It's only talking to people like you or seeing normal people that I get upset and realise how abnormal I am' (2.8).

**Understanding the behaviour:** Some carers showed a particular interest in trying to understand and make sense of the behavioural manifestations of dementia in the person they cared for. WG did so on several occasions, such as 'I get his ironing done. He sits down and goes to sleep and that's when I crack on with things. I think he's frightened of ironing now. He maintains his new ironing board is wobbly, but I think he's afraid' (2.18).

**Managing the behaviour:** Again, WG gave an example of this, 'I phone him every day to tell him what day it is, whether he needs to stay in, or whatever. He has a board where I put it all in big writing' (2.37).

### Sub theme - caring

**The emotional impact of caring:** MP said 'I alternate between hoping my mother will die, and feeling bad about that, 'cos I just... I'm struggling' (3.24).

**Physical and practical impact of caring:** When asked about stressful aspects of caring, EB responded 'The fact that I have to do things every day like get up early in the morning even if I feel like lying on... The limits on my time' (2.11).

**Limits to the care provided:** NJ was one of the carers who was clear that there were limits to what she could provide in the way of care for her father. She said 'There are things I'd refuse to do – like if he needed nursing care. I know there are people who say they would take that on, but I can't. I've gone as far as I can. I've gone as far as I can cope with, let's put it that way' (2.19).

**Not knowing what it would be like:** this was raised by two of the adult child carers, NJ and EB. EB said 'I remembered the mum I used to have, not the one I have now. So I got on a plane and went to The States to collect her, and found the confused old woman who needs total care...' (1.12) and later 'Initially I was coping... but as the months went by I realised she wasn't going to get any younger or better. If I had known, I wouldn't have taken it on. My sister had coped for 15 years and we thought she was just old and forgetful... we didn't know she had dementia' (1.16).

**Lack of choice in taking on or continuing to care:** this was expressed by the same two carers who felt they had not realised what it would be like to care for their parent. For example, EB said 'I have to, I suppose, because there's no-one else to do it' (2.16).

### Sub theme – physical health

Some of the carers had serious physical health problems themselves, which they raised in the interviews. For example, MP said 'I had a quadruple heart by-pass four years ago and the angina symptoms have come back. I'm not feeling good right now. Not good at all' (2.12).

### Sub theme – positive aspects of the situation

Those things that carers found satisfying were asked about explicitly in the interviews, and some carers added things they felt they had gained from the situation in response to other questions. For example, HS said 'I'm satisfied in a sense, looking after her and that. I'm glad I can do it really...' (2.16). NJ said '...I suppose we now live in a nicer house; I'm more comfortable at home than I was before, and that's a big plus... (2.32)... I've met a lot of nice friends through my father and my position, and I've learnt I can help other people in the same position... that gives me a lot of satisfaction' (2.35).

### Sub theme – self

This sub theme incorporated issues relating to self concept, perceived competence and to values and beliefs.

Self concept: ME had been talking about all the ways in which she helped her mother, and said 'Five years ago I would have thought "I can't do that!"' (2.13). And NJ said 'It makes me feel grown up, looking after a parent' (2.27).

Perceived competence: Referring to her sense of competence, NJ said 'I suppose in some ways it's better, because I've had to cope with things I hadn't done before...' (2.12). EB said 'My competence is linked to my physical health' (2.1) and went on to explain how an injury that had caused her to take early retirement from work was exacerbated by caring for her mother.

Values and beliefs: Although this was not something explicitly raised by most carers, to WG it was clearly very important. When asked what helped her continue as her father's carer she said, 'Basically, I'm a Christian... I think it sets a standard for yourself, to always be kind to him' (4.13).

### **Main theme – the relationship between the care provider and the care recipient.**

This theme consisted of sub themes to do with changes in the relationship, the carers' views of roles and responsibilities within the relationship and notions of reciprocity.

### Sub theme – changes within the relationship

ME had said she thought the contact she had with her mother was an aspect of care she managed well, '...She tells me how much it means to her and I know it brings her a lot of pleasure. I find it all very embarrassing... because of the relationship we had before. I was brought up with no love and hugs and we never talked about how we loved each other. And I'm still hurt that she accused me of taking things from the home – there's a lot of anger there... She senses a deterioration in the relationship' (1.30).

### Sub theme – roles and responsibilities within the relationship

HS, when asked how she had taken on the role of carer for her mother, said 'Living here, I just naturally... you just naturally do it. This is my family home' (1.13). When asked the same question, MP gave a description of her relationship with her mother going back to her childhood, saying 'When I was eight my father went to the war, and my sister was two. And he looked me straight in the eye and said "Take care of your mother" and I have always taken that on. In reality not, because my father returned from war, and didn't die till 1979, and my mother has been more dependant on my sister and myself since then' (2.6).

### Sub theme – reciprocity

This was mentioned by several carers. For example, ME said '... She was very supportive when I was younger, she helped with the children, and I owe her a lot... (2.6)... She cared for me and the roles are reversed now' (2.13).

### **Main theme – services**

A number of comments were made about services that had been received, either by the carer or the care recipient. EB said 'Lack of information. I didn't know where to begin. I went to the GP because I thought there was a problem with mum, but it was a friend at work who said I could apply for financial help. It was all piecemeal. It would have been good to find an Asian organisation, because my mother is the only one in her group...' (2.21). It is worth noting that EB had been employed by the NHS for many years prior to her retirement, so was familiar with the health care system.



### **Main theme - family**

It was decided to make the family a theme of its own, since families were not just seen as a source of social support, which was more the case with spouse/partner carers. Sometimes there were conflicts about where the limits of family care should lie and how much different people within the family did. WG had mentioned her family quite a lot in her interview and had referred to her resentment with her sisters. Later on she said 'I suppose I'm happier that atleast my sister in Scotland is more interested, so I can unload on her now and I see that in the future it won't be just me, I can tell her too, and that'll give me a bit of a boost, because my younger sister just wants to put him in a Home. She says it in the kindest way. She just thinks dad is ruining my life, which in some ways is true, but I love him' (3.30).

**Summary of results from the postal survey responses to the  
Carers Assessment of Difficulties Index (CADI)**

The table below shows the summary of responses from the postal survey to the CADI. The columns show the number of people who indicated an item sometimes or always applied to them, and how many people found that item very stressful or moderately stressful. The total number of respondents was 40.

ITEM	SOMETIMES/ ALWAYS APPLIES	VERY STRESSFUL	MODERATELY STRESSFUL
I don't have enough private time for myself.	38	11	18
I can feel helpless/not in control of the situation.	24	6	13
I can't devote enough time to other members of my family.	18	4	8
It causes financial difficulties.	7	1	2
The person I care for can play me up.	29	11	12
The person I care for is immobile/has problems getting about.	27	3	15
Professional workers don't seem to appreciate the problems carers face.	13	1	6
It restricts my social life/outside interests.	31	8	12
It can put a strain on family relationships.	22	8	11
It is physically tiring.	32	11	10
The person I care for can demand too much of me.	28	7	11
I no longer have a meaningful relationship with the person I care for.	21	5	10
The person I care for needs a lot of help with personal care.	31	5	11
The person I care for doesn't always help as much as they could.	24	3	15
My sleep is affected.	31	9	11
Relatives don't keep in touch as often as I'd like.	24	5	8
I feel angry about the situation.	30	8	15
I can't see friends as often as I'd like.	25	4	12
My emotional well-being suffers.	28	4	17
I can't have a break or take a holiday.	26	8	9

My standard of living has fallen.	12	0	7
The person I care for does not always appreciate what I do.	21	6	8
My physical health has suffered.	20	4	12
The person I care for is incontinent.	20	5	10
The behaviour of the person I care for is a problem.	28	5	16
There is no satisfaction to be gained from caring.	18	3	8
I don't get enough help from the health and social services.	12	3	6
Some family members don't help as much as they could.	22	6	11
I can't relax because of worry about caring.	33	9	16
I feel guilty about the situation.	17	2	11

## Summary of results from the postal survey responses to the Carers Assessment of Satisfaction Index (CASI)

The table below shows the number of people who rated each item as applying to them and giving a great deal of satisfaction or quite a lot of satisfaction. The total number of respondents was 40.

ITEM	A GREAT DEAL OF SATISFACTION	QUITE A LOT OF SATISFACTION
Caring has allowed me to develop new skills and abilities	5	8
The person I care for is appreciative of what I do	11	8
Caring has brought me closer to the person I care for	8	9
It's good to see small improvements in their condition	18	7
I am able to help the person I care for reach their full potential	10	6
I am able to repay their past acts of kindness	14	6
Caring provides a challenge	10	5
Despite all their problems the person I care for does not grumble or moan	12	3
It is nice to see the person I care for clean, comfortable and well turned out	27	6
Caring enables me to fulfill my sense of duty	15	8
I am the sort of person who enjoys helping other people	12	11
I get pleasure from seeing the person I care for happy	28	5
It's good to help the person I care for overcome difficulties and problems	20	8
It's nice when something I do gives the person I care for pleasure	19	13
Knowing the person the way I do, means I can give better care than anyone else	18	4
Caring has helped me grow and develop as a person	3	5
It's nice to feel appreciated by those family and friends I value	7	11
Caring has strengthened close family ties and relationships	3	7
It helps to stop me from feeling guilty	3	5
I am able to keep the person I care for out of an institution	23	7
I feel that if the situation were reversed the person I care for would do the same for me	20	5
I am able to ensure that the person I care for has their needs tended to	21	12

Caring has given me the chance to widen my interests and contacts	2	4
Maintaining the dignity of the person I care for is important to me	29	6
I am able to test myself and overcome difficulties	5	5
Caring is one way of showing my faith	7	2
Caring has provided a purpose in my life that I did not have before	4	0
At the end of the day I know I will have done the best I could	26	7
Caring is one way of expressing my love for the person I care for	26	4
Caring makes me feel needed and wanted	5	11